

# Towards an AIDS free generation in Uganda (TAFU)

A participatory project evaluation in Soroti, Mubende, Mityana, Ntungamo and Kyenjojo Districts

Final Report - June 2023



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## **Abbreviations**

AIDS Acquired Immune Deficiency Syndrome

ANC Antenatal Care

ART Anti-Retroviral Therapy

CBO Community Based Organisation
CHAU Community Health Alliance Uganda
CoRP Community Resource Persons

CSO Civil Society Organisation
DHT District Health Team

eMTCT Elimination of Mother-to-Child Transmission of HIV

FGD Focus Group Discussion

HBC Home Based Care
HC Health Centre
HC I Health Centre one
HC II Health Centre two
HC III Health Centre three
HC IV Health Centre four

HIV Human Immune-deficiency virus

HNU Health Need Uganda

HSS Health Systems Strengthening

MoH Ministry of Health

NAFOPHANU National Forum of People Living with HIV/AIDS Networks in Uganda

NGO Non -Governmental Organisation
OVC Orphans and Vulnerable Children

PLHIV People Living With HIV

PMTCT Prevention of mother-to-child transmission of HIV TAFU Towards an AIDS Free Generation in Uganda

STI Sexually Transmitted Infection UAC Uganda AIDS Commission

VHT Village Health Team

VSLA Village Savings and Loan Association

### **Abstract**

#### **Background**

While Uganda has made progress in HIV prevention and care in general, many barriers at family, community and health facility levels hinder paediatric HIV prevention, enrolment and retention of children in care. Besides, most of the interventions by the government are based at the health facility. While the country promotes use of Village Health Teams (VHTs)/community health workers in the prevention and management of childhood illnesses, VHTs were not trained nor involved in prevention and treatment of HIV, before the initiation of TAFU. Aidsfonds initiated the 'Towards an AIDS Free Generation in Uganda' (TAFU) program, aimed at reducing new HIV infections among infants and increase numbers of HIV positive children (aged 0-14) on treatment. The TAFU program started in 2015 in 5 districts in Uganda: Napak, Moro, Serere, Mityana and Mubende (TAFU 1). Building on successes of the program in the first phase (2015 – July 2017), the TAFU program was scaled-up to three new districts: Soroti, Kyenjojo and Ntungamo and continued in Mityana and Mubende districts (TAFU 2- 2017-2019). After 2019, TAFU continued in the 5 districts of Soroti, Kyenjojo, Ntungamo, Mityana and Mubende which ran between August 2019 -May 2022 (TAFU 3). The 3rd phase of the program was implemented by four Ugandan nongovernment organizations: Health Need Uganda (HNU) in Soroti, Community Health Alliance Uganda (CHAU) in Mubende, Mityana and Kyenjojo Districts, Appropriate Revival Initiatives for Strategic Empowerment (ARISE) in Ntungamo District and The National Forum of People Living with HIV/AIDS Networks in Uganda (NAFOPHANU) in all the five districts and at national level. This endline research evaluated TAFU 3 and sought to document the perspectives of all stakeholders, including beneficiaries, regarding project contribution, challenges and lessons learnt in relation to paediatric HIV prevention and treatment services in the target areas.

#### Methods

This cross-sectional participatory evaluation was conducted in all the five TAFU 3 program areas. Data was collected through 1) a review of project reports including amongst others the baseline research, TAFU 2 reports and routine health facility reports of 23 health facilities, 2) 31 focus group discussions (FGDs) with mothers in PMTCT/eMTCT programme, partners of women attending eMTCT, children and adolescents living with HIV, caregivers of children living with HIV, networks of people living with HIV and Village Health Team members (VHTs), 3) 43 key informant interviews with district officials involved in eMTCT and Paediatric HIV care, health workers, leaders of PLHIV networks, staff of partner agencies and staff of other programmes on eMTCT/Paediatric HIV and 4) 11 in-depth interviews with selected mothers that were part of the Ugandan PMTCT programme implemented by the ministry of health and with support from partner programs like TAFU, children and adolescents living with HIV and their caregivers at TAFU supported health facilities. For the qualitative data analysis a content thematic approach has been used which involved reading and grouping findings according to key themes, and excel has been used for quantitative data analysis.

#### Results

#### **Key TAFU Interventions**

Since 2015, interventions aimed at strengthening community systems, and creating linkages between health care facilities and communities for paediatric HIV prevention and care have been implemented under the TAFU program. Partner CSOs together with district officials identified and built the capacity of VHTs and community resources persons to serve as bridges between communities and health care facilities. The community structures identified pregnant and lactating women and referred them to health facilities for HIV testing. Those found to be living with HIV were enrolled into HIV care for themselves and for prevention of vertical transmission of HIV. The TAFU program also built the capacity of community resource persons/structures to trace, support, refer and follow-up children living with HIV and to increase community awareness on paediatric HIV prevention in areas where VHTs and CoRPs reside. The program mobilized caregivers of children living with HIV and supported them to form village savings and loan associations to address the socio-economic barriers they face such as poverty, stigma and limited knowledge on care for children living with HIV. At health facility level, the TAFU program, enhanced coordination mechanisms among VHTs/Community resource persons and health facilities for tracing, identification, care, referral and follow-up of children living with HIV. The program also supported partners to lobby and advocate for improved paediatric HIV prevention and care services in target areas.

#### Key achievements

As part of the TAFU 3 program, 670 VHTs and community resource persons were trained on paediatric HIV prevention and care. The VHTs and community resource persons conducted 16,478 household visits to educate family members on HIV Counselling and Testing (HCT), elimination of mother to child transmission of HIV (eMTCT) and care for children living with HIV. For children and women living with HIV, household visits were used to assess and provide support for ART adherence as well as follow-up of those who missed clinic appointments or lost to follow-up and re-engaging them to care.

Through training, mentorship, home visits and regular interface of VHTs/CoRPs and health facility staff, the TAFU program strengthened community-health facility systems and increased identification, referral, enrolment and retention of children and women living with HIV in care. In 2022,1,137 children and adolescents living with HIV were in care at the target health facilities at the end of TAFU 3 compared to 1,065 in 2019 at the end of TAFU 2 and 699 at baseline in 2017. Taken together, an additional 438 children and adolescents living with HIV were supported by the program to enrol or re-engage in care at target health facilities between 2017 and 2022.

During the TAFU 3 intervention period 5,532 pregnant and lactating women were referred for ANC and HIV testing of whom 4,989 (90%) completed referral and 341 women who tested HIV positive were enrolled in care. The community structures supported by TAFU sensitized pregnant women to attend ANC and deliver at health facilities and most women living with HIV gave birth to HIV negative babies. Evaluation findings further revealed that 3,425 children up to 14 years were referred for HIV testing of whom 2,880 (84%) were tested; 46 of them tested HIV positive and were enrolled in care.

Evaluation findings revealed that VHTs and CoRPs also visited and supported children and women living with HIV in target communities who received HIV care at higher level health facilities

particularly at county level (HC IVs) and at hospitals located outside the TAFU intervention areas. Thus the impact of the program goes beyond the target health care facilities.

The TAFU3 program facilitated the formation and support of 48 community VSLAs for caregivers to strengthen the capacity of families to address the socio-economic needs of children affected and living with HIV and their caregivers. These VSLAs benefited 1,442 members, 206 children living with HIV and 1,245 HIV negative children. TAFU 2 supported 53 VSLAs which benefited 1,490 members while TAFU 1 supported 43 VSLAs with 1,008 members. The VSLAs provided space that allowed members living with HIV to freely share experiences regarding their own care and that of the children living with HIV under their care. The VSLAs provided opportunities for experience sharing and for VHTs, CoRPs and health care workers to educate caregivers on paediatric HIV prevention and care leading to improved knowledge among VSLA members. Caregivers across all the TAFU districts had borrowed funds from VSLAs to pay for transport to health facilities, start income generation activities or to meet the nutrition and education needs of their children. Overall, the VSLAs supported by TAFU were a source of social, economic and psychosocial resources that enhanced caregivers' abilities to care for children living with HIV.

The TAFU program supported the formation, training and provision of VSLA kits to 21 VSLAs for VHTs and CoRPs which were appreciated as a source of credit for CoRPs (volunteers) to start income generation activities to support their families. These VSLAs provided opportunities for VHTs to meet monthly, to save money, to access credit, share experiences and provide feedback to health workers regarding their community activities. In this regard, VSLAs for VHTs and CoRPs are likely to increase chances for continuity of VHT and CoRPs activities.

TAFU program facilitated quarterly dialogue sessions involving HIV implementing partners, VHTs, CoRPS, health workers and district officials. Dialogue meetings provided a unique space to raise awareness on paediatric HIV, identify and address challenges affecting children and women living with HIV.

During the COVID-19 outbreak, challenges related to stigma and discrimination, HIV status non-disclosure, gender based violence, the high cost of transport to health facilities and shortage of food were discussed and addressed. The TAFU partners distributed food to vulnerable households and supported VHTs, CoRPs and health workers to provide anti-retroviral drugs to children and women living with HIV who could not access health facilities due to transport challenges. The food and ART supplies improved adherence and viral load suppression. In addition, lessons learnt from the program were shared. Community dialogue meetings increased awareness about eMTCT and paediatric HIV, and made visible the challenges faced by children and women living with HIV and the need for collective action among stakeholders to address them. Evaluation findings indicate that due to TAFU interventions, challenges of non-disclosure of HIV and stigma have reduced, but are still prevalent reflecting a need for interventions to promote disclosure and fight HIV related stigma.

#### Key challenges

Whereas TAFU interventions at community and health facility levels, helped to address the challenges hindering children and women living with HIV to effectively utilize HIV services, several challenges still exist at individual, family, community and health system levels. The key challenges during implementation of TAFU 3 included shortage of food, poverty, stigma, non-disclosure, low male involvement and migration (individual and family levels) as well as limited geographical scope, disrupts of services by COVID-19, stock out of critical HIV supplies, delays at health centres, few trained volunteers, challenges in tracking referrals by VHTs and CoRPs to health facilities and long

distance to health care facilities (health facility level). Lack of resources at health facility, sub-county, district and national levels for community activities, and high community expectations were other key contextual challenges. These challenges require long term multi-stakeholder interventions. At program level, limited geographical program coverage, limited number of community resource persons trained, some community members sensitised about paediatric HIV prevention and care moving out of the program, lack of reference materials and logistical support especially for mentored CoRPs for use in their work and inadequacies in documenting and tracking program outputs of VHTs and CoRPs were key challenges.

#### **Lessons Learnt**

Building linkages between community resource persons and health facilities improves identification, linkage and retention of children and women living with HIV in care. When VHTs and CoRPs are trained, mentored and linked with health facilities through regular joint progress review meetings, sharing of information, development and implementation of action plans, VHTs are a crucial linking pin between communities and health facilities.

Community resource persons and village health team members who doubled as expert clients are preferred by caregivers and children living with HIV as CoRPs and VHTs to reach and support children and women living with HIV. These draw on personal experiences living with HIV to support others especially those newly diagnosed with HIV. They were also viewed as unlikely to promote stigma compared to those not living with HIV.

Continuous training, mentorship and supervision of community resources persons to improve their knowledge and skills are important to improve effectiveness given the ever emerging evidence on HIV prevention and care as well as the changing needs of target groups.

Children and women living with HIV continue to face stigma at home, community and health facilities. Thus, activities that support children and women to build resilience against stigma as well as those geared at stigma reduction at home, in the community and health facilities should be sustained.

Health facility challenges such as stock out of critical HIV supplies, having a limited number of health workers available at the facilities, lack of resources for community activities and sustainable mechanisms to track the contribution of CoRPs limit the success of paediatric HIV prevention and care interventions. These require broader and sustained health system improvement interventions around all the six health system building blocks recommended by the World Health Organisation-service delivery, health workforce, health information system, financing and leadership.

Shortage of food remains a major barrier for women and children to adhere to HIV treatment and subsequently to viral load suppression. The COVID-19 pandemic and related lockdowns compounded food shortages. Food relief provided as part of COVID-19 response projects by TAFU partners was highly appreciated and contributed to retention in care and identification of children and adults living with HIV who had been lost to follow-up or not in care.

Village Savings and loan associations provided a good avenue for TAFU partners to address the economic and psychosocial challenges faced by children living with HIV and their caregivers. These groups facilitated access to credit to start or improve income generation activities, experience sharing among caregivers and health education talks on paediatric HIV prevention and care integrated in VSLA group meetings.

The VSLAs for VHTs and other community resource persons were a source of motivation for these community structures and hold potential for continuity of community-facility activities. These VSLAs provide opportunities for CoRPs to continue meeting, share experiences and continue learning from each other as well as enabling them to addressing their individual and family economic needs.

Linkage and involvement of sub-county and district officials including community development officers, district production and commercial officers in training and monitoring VSLA groups provides opportunities for such groups to access additional financial and technical support from government programmes.

Village Savings and Loan Associations provided an opportunity and safe space for members living with HIV to share experiences including on fighting HIV related stigma as well as overcoming side effects of ART through ART literacy education talks and experience sharing including tips on addressing ART related side effects

Joint project coordination and review meetings involving district health teams and officials from other departments such as community development, agriculture and education provided an important space for stakeholders to appraise TAFU interventions, share lessons, promote program ownership and increase chances for sustainability. Working with local government structures effectively requires allocating resources to aid their participation in programme implementation and monitoring.

While the local government structures and the Ministry of health appreciate the role of VHTs and CoRPs in bridging the gap between communities and health facilities, inadequacy of resources for community system strengthening remains a key challenge.

#### **Conclusions**

The TAFU program strengthened community systems for finding, testing, referral, follow-up and support of women and children living with HIV through training, support supervision and mentoring of VHTs and other community resource persons. The TAFU program improved uptake and retention of women and children in paediatric HIV prevention and care services.

During the project period, TAFU program initiated and supported 48 village savings and loan associations (VSLA) for women and caregivers of children living with HIV in the target communities. Overall, 1,442 women living with HIV and caregivers of children living with HIV have been supported through VSLAs. The VSLAs under TAFU are sources of economic empowerment, psychosocial support, knowledge and skills and motivation to initiate and remain in care.

The TAFU program initiated and supported 21 VSLAs for VHTs and CoRPs. Four of these groups in Soroti were initiated in TAFU 2. These have enabled VHTs and CoRPs to mobilise savings, meet regularly and borrow to start income generating projects to meet personal and family needs. As such these VSLAs were a source of motivation for VHTs and CoRPs and provide opportunities for likely continuity of community activities.

The TAFU program increased community awareness about paediatric HIV prevention and care and contributed to reducing HIV related stigma. The program also increased the visibility of paediatric HIV and needs of children living with HIV at community and district levels.

The COVID-19 and related lockdowns exacerbated challenges faced by women and children living with HIV and their caregivers. Challenges of access to health facilities, cost of transport to health facilities, shortage of food, stigma and violence increased during the COVID-19 outbreak and negatively affected ART adherence. As such the TAFU program provided food to the most vulnerable families, supported health education and counselling for ART adherence and enabled health workers and VHTs to distribute ARVs to community members who could not access health facilities. These findings demonstrate a need for HIV implementers, government and donors to invest more in building community-health facility linkages for resilient health systems to better meet the needs of the most vulnerable members of communities including children especially in times of disasters and outbreaks.

Overall, the TAFU program contributed to strengthening linkages between health care facilities and communities for identification, follow-up, tracing and referral of women and children living with HIV between health facilities and communities. TAFU program enhanced the capacity of VHTs and CoRPs and linked them to health facilities for support and collaboration. Taken together, the TAFU program interventions complemented paediatric HIV services by the Ministry of Health and partners in Uganda and contributed to increased enrolment and retention in HIV care for women and children in target districts. The community structures supported by the TAFU program, particularly VHTs and CoRPs as well as the VSLAs are likely to continue providing services to children living with HIV and their caregivers beyond the program period. While the TAFU program, contributed to a reduction in non-disclosure of HIV status and stigma these are still prevalent in intervention areas and require sustained interventions. Evaluation findings also revealed a need to integrate food security and nutrition interventions in community health interventions, improving systems for support, documentation and tracking the contribution of VHTs and CoRPs while scaling up the model.

#### Recommendations

Aidsfonds and partners should mobilise resources to scale-up the TAFU model in current and additional districts for wider impact and learning. In intervention districts, the program should cover all sub-counties and leverage on community structures initiated in the past phases of TAFU such as VHTs, CoRPs, VSLAs, health workers, school and district authorities to build capacity in additional sub-counties and districts.

At the global level, Aidsfonds should advocate for other donors to invest in community strengthening approaches like TAFU.

In Uganda, TAFU partners should engage more with the Ministry of Health, other national level and international actors in paediatric HIV prevention and care to increase awareness about the model and advocate for more resource allocation for the implementation of community system strengthening interventions for paediatric HIV prevention and care.

Continue to strengthen linkages of TAFU with multi-sectoral teams at district and national levels beyond health to include community development, education, agriculture and production departments especially regarding the activities of VHTs, CoRPs VSLAs and schools.

It is important for all actors in paediatric HIV care to increase support to families of children affected by HIV to enhance food security in a sustainable manner. This can involve training family members in basic agronomic practices and enabling them to access seeds to start backyard/kitchen gardens to grow vegetables and fast maturing fruits for home consumption and surplus for sale. In times of crisis, as was the case during the COVID-19 outbreak and related

lockdowns, vulnerable families should be identified and provided with food relief and home based drug refills to sustain ART adherence.

Increasing participation of district officials in planning, implementation and review of program activities should be prioritized for sustainability. These include members of the District Health Team and officials from departments of community development, education and agriculture who should be involved in training and supervision of health workers, community resource persons, VSLA groups and school activities.

Actors working with community resource persons should support them to form VSLAs and training them on income generation activities as strategies to support them meet their financial needs. In all districts some health workers had joined VHT/CoRPs VSLAs thus providing an added benefit of continued interaction and support between VHTs and health workers.

District and national level actors should continue to engage and build the capacity of District Networks of people living with HIV in community mobilisation, education about paediatric HIV care to improve treatment literacy and advocacy. These networks play a critical role in monitoring and advocating for improved HIV care services.

Actors in health promotion programs should continuously find points to integrate paediatric and adolescent HIV prevention and care with other programs aimed at promoting child, adolescent and maternal health to maximize benefits to target communities.

Stakeholders involved in community system strengthening should work collaboratively with the Ministry of Health to harmonise indicators and monitoring systems to track and report on the contribution of community resource persons on eMTCT, paediatric and adolescent HIV care.

Health facilities should further be strengthened by recruiting additional health workers and ensuring adequate supply of critical HIV supplies including ARVs and HIV test kits.

District health team members should continuously monitor and address stigma at health facilities.

# 1 Introduction and background

#### 1.1 Introduction

In this report, findings of a participatory project evaluation for the Towards an AIDS Free Generation in Uganda (TAFU 3) project implemented in 5 Ugandan Districts of -Soroti, Mubende, Mityana, Kyenjojo and Ntungamo are presented. The project sought to 1) reduce the number of new HIV infections among children and 2) ensure more children living with HIV are enrolled and retained on treatment.

The TAFU program started in 2015 in 5 districts in Uganda: Napak, Moroto, Serere, Mityana and Mubende (TAFU 1). Building on successes of the program in the first phase, in 2017 – July 2019 the TAFU program was scaled-up to three new districts: Soroti, Kyenjojo and Ntungamo and continued in Mityana and Mubende districts (TAFU 2). The program continued in these 5 districts between August 2019 - May 2022 (TAFU 3). This report is submitted to Aidsfonds and partners in Uganda in relation to the endline survey for the TAFU 3 program. The end line was conducted using participatory applied research methodology to elicit perspectives of stakeholders including beneficiaries, health care workers, district officials, networks of people living with HIV, VHTs and partner agencies regarding program contribution in relation to paediatric HIV prevention and treatment services in the target areas.

Aidsfonds and four Ugandan non-government organizations: Health Need Uganda (HNU) in Soroti, Community Health Alliance Uganda (CHAU) in Mubende, Mityana and Kyenjojo Districts, Appropriate Revival Initiatives for Strategic Empowerment (ARISE) in Ntungamo District and The National Forum of People Living with HIV/AIDS Networks in Uganda (NAFOPHANU) in all the districts and at National level worked together to implement the project. Collaboration with the District Health Service departments in intervention districts was key during project implementation.

This participatory evaluation was conducted between July and August 2022 to document program achievements, challenges encountered and lessons learnt during project design and implementation in 5 Ugandan Districts (Soroti, Mubende, Mityana, Kyenjojo and Ntungamo). In addition, the evaluation explored strategies adopted by TAFU partners to ensure continuity of HIV services during the Covid-19 pandemic.

#### 1.2 Overview of health system, Paediatric HIV and Services in Uganda

Public health services in Uganda are provided at community, health centre (HC) and hopsital levels. The levels of health system follow administrative units; at community level (HC I), parish (HC II), sub-county (HC III), county (HC IV), district (district hospital), regional (regional referral hospital), and national level (national referral hospital). The community level (HC I), services are provided mainly by village health teams (VHTs). This level has no physical location. The HC I is followed by HC II which has a physical location, provides outpatient services, antenatal care, HIV testing, immunization and community outreach services. The next level is HC III which provides all the services provided at HC II, plus maternity and laboratory services, ART and has a general ward for patients. Health Centre IV provides all services at HC III and surgical services. Hospitals offer all services provided at HC IV and specialized care. TAFU program interventions mainly focused at lower HC levels such as community level, parish level and sub-county level.

Uganda has made progress in the fight against HIV. Such efforts include ongoing scale-up of services for elimination of vertical transmission of HIV and care for adults and children living with HIV. Most of these efforts have mainly focused at the level of health facilities (1). Examples of such efforts include rolling out eMTCT to lower level Health Centres (HC II and IIIs) involving integration of routine HIV counselling and testing within maternal and child health services as an entry point into the programme; implementation of Option B+ where all pregnant and lactating women identified as HIV positive are starting on lifelong ARVs irrespective of CD4 cell count(2); and currently the Test and Treat policy for all people living with HIV (including children) are initiated on lifelong ARVs regardless of CD4 count and HIV clinical stage (3-6). The Uganda Ministry of Health and partners also strive for Early Infant Diagnosis for HIV exposed children; are conducting community mobilisation and education through the media, routine health education at health centres and during community outreach programmes geared at increasing demand for eMTCT and Paediatric HIV care. Peer mothers and family support groups mainly based at health facilities are other avenues being used to educate communities and provide support for eMTCT and Paediatric HIV prevention and care.

With Routine HIV testing integrated in most maternal and child health care services in Uganda, over 95% of pregnant women attending ANC are tested and receive HIV results. Due to sustained expansion of eMTCT, marked reduction in new HIV infections among children has been noted. For instance, new HIV infections in children reduced from 31,000 in 2011, to 15,000 in 2013 and to 5,200 in 2014. However, challenges remain especially in realizing an AIDS free generation. In 2015 about 147, 000 Ugandan children (0-14 years) were estimated to be living with HIV (7). Only 42% of these children were on treatment. New 2016 estimates of UNAIDS show a different picture: an estimated 96,000 children are living with HIV in Uganda and the Paediatric Anti-retroviral Treatment coverage is now estimated at 62% (8). Furthermore, treatment coverage for children living with HIV still lags behind that for adults reflecting continued unmet need (9). The unmet need for paediatric HIV care persists in the context of very high Antenatal Care attendance (95%) attendance and increased availability of PMTCT services. Disparities also remain in use of antiretroviral drugs for eMTCT: 94% for mothers and 25% among HIV exposed infants(10). Besides, many children continue to be lost to follow-up, which is a missed opportunity for paediatric HIV prevention and optimising care. According to routine data from the Ministry of Health, in 2015 about 30% of children identified as HIV positive were lost before enrolment.

HIV exposed children (born to women living with HIV) are being tested as part of the PMTCT program (first test should be at their first contact with a health system, at birth or before 6 weeks and the second test when they are 18 months old). The uptake of the first test is estimated at 58%, (4) and the second test at 18 months only at 30%.

Many barriers at health facility, community and family levels continue to limit use of paediatric HIV prevention, enrolment and retention of children in HIV care. The baseline study conducted as part of the TAFU project revealed that linkages between health care facilities and communities were weak. Systems for follow-up, tracing and referral of women and children living with HIV between health facilities and communities were in general lacking or weak leading to high rates of loss to follow-up. Where community structures existed, they lacked capacity, were not well coordinated and not linked to health facilities. The general lack of awareness among community members on paediatric HIV, stigma and economic barriers also hindered children living with HIV from enrolling and remaining in HIV care (1, 11).

As a response, the government and nongovernmental organisations have put in place several strategies to address these barriers. One such intervention is the Towards an AIDS Free Generation in Uganda (TAFU) program implemented in 5 Districts of Soroti, Mubende, Mityana,

Kyenjojo and Ntungamo. The project ended in May 2022 and this report presents results of a participatory evaluation conducted between July and August 2022.

#### 1.3 The TAFU Program Goal, Objectives and Approach

#### **TAFU Program Goal**

The overall goal of this program is to reduce the number of new HIV infections among infants and increase the number of HIV-positive children on treatment in the target districts.

#### Specific objectives of the program are to:

- 1. Improve uptake and retention of HIV-positive mothers and exposed infants in PMTCT-care;
- 2. Increase the number of children tested (both infants and children up to 14 years)
- 3. Increase access to and retention in life-long care and treatment for HIV-positive children

#### 1.4 TAFU Program Model/Approach

The program used a 3-fold approach by supporting 1) families with HIV positive children 2) the communities they live in and 3) the lower level health system. The program focused on strengthening community systems and creating linkages between the health care facilities and communities (figure 1). Community Systems which include community members, community resource persons (village health team members, persons living with HIV, teachers, community and religious leaders), community groups (village savings and loan associations and village health groups) and institutions such as schools, community-based organizations and non-governmental organizations were identified and supported to serve as bridges between communities and health care facilities. Community systems were also meant to provide a feedback loop on the quality of health services to serve as a basis for advocacy for district authorities and partner HIV implementing agencies to improve the quality and delivery of HIV and other health services.

Figure 1: The TAFU Program Model



As shown in the figure 1, the TAFU program sought to bridge the gap between communities and health facilities to prevent mother-to-child-transmission of HIV and to ensure HIV-positive mothers and HIV exposed children and those living with HIV enroll and remain in care. Box 1, presents key focus areas of the TAFU program approach.

#### Box 1: Focus of TAFU approach and interventions

Work with the families to address their socio-economic barriers by:

- creating awareness on paediatric HIV care and support
- addressing stigma at household level
- facilitating economic empowerment of affected families
- assisting families in coping with other (individual) barriers to seeking HIV prevention, testing and care services for children

Work with community structures including networks of people living with HIV and Village savings associations and resource persons to address structural barriers at community level, by:

- creating awareness on paediatric HIV care and support at community level
- addressing stigma within community structures
- starting and strengthening peer support groups
- building the capacity of community resource persons/structures to trace, support, refer, follow-up children living with HIV

Work with the VHTs, Health Centres II and III( HCII and HCIII) to create a strong coordinated system of tracing, identification, care, referral and follow-up for children living with HIV by:

- improving the coordination between VHTs and Health Centres
- creating and strengthening linkages between HCs and community structures
- building the capacity of VHTs to play the linking role between HFs and communities
- advocating to HFs, districts, government to use other entry points to find and link HIV positive children to care

Lobby and advocacy and align activities with other relevant health partners to improve the quantity and quality of service delivery at health facility level, eg training of health workers on paediatric ART and counselling.

Working through a community system approach TAFU sought to complement the ongoing interventions that are largely health facility based. This participatory evaluation assessed TAFU approach and interventions from the views of project implementers and beneficiaries.

#### 1.5 General objective of the evaluation

To assess the achievements, facilitators, challenges and lessons learnt from the Towards an AIDS Free Generation Program implemented in 5 Ugandan Districts of Soroti, Mubende, Mityana, Kyenjojo and Ntungamo on utilization of eMTCT and Paediatric HIV services.

#### Specific objectives

- 1. To assess major achievements of TAFU program as perceived by stakeholders (implementers and beneficiaries).
- 2. To assess factors that influenced project effectiveness (facilitators and challenges in relation to improving delivery and utilization of eMTCT and paediatric HIV care services)

- 3. To document innovative strategies adopted by project partners to ensure continuity of eMTCT and paediatric HIV services during the Covid-19 pandemic and related restrictions in the 5 target districts.
- 4. To document lessons learnt during the design and implementation of the TAFU project in the 5 target districts.

# 2 Study methodology

#### 2.1 Study Area and Selection

The evaluation study was conducted in all the five project intervention districts of Soroti, Mubende, Mityana, Kyenjojo and Ntungamo. All the 20 program sub-counties and 23 health facilities were included in the study (Table 1).

Table 1: Summary of Study areas by region and district/ partner

Region	District/Partner <sup>1</sup>	Sub-Counties	Health Centres
Eastern	Soroti (HNU)	Kamuda	Kamuda HC III
		Asuret	Asuret HC III
			Lalle HC II
		Tubur	Tubur HC III
		Gweri	Gweri HC III
			Aukot HC II
South	Ntungamo (ARISE)	Rubaare	Rubaare HC IV
Western	_	Ntungamo	Ntungamo HC IV
			Butare HC III
		Nyakyera	Nyakyera III
Central	Mubende (CHAU)	Kitenga	Kitenga HC III
		Kibalinga	Kibalinga HC III
		Madudu	Maddudu HC III
		Nabingola	Nabingola HC III
	Mityana (CHAU)	Ssekanyonyi	Ssekanyonyi HC IV
		Busunju TC	Busunju HC II
		Namungo	Namungo HC III
		Kikandwa	Kikandwa HC III
		St. Padropio	St. Patropio HC III
Western	Kyenjojo (CHAU)	Bugaaki	Nyamabuga HC III
		Katooke	Katooke HC III
		Kyembogo	Kyembogo Holly Cross HC III
		Butunduzi	Butunduzi HC III
4	5 Districts	20	23 (HCIV=3; HCIII=17; HCII=3)

#### 2.2 Study Design

This was a descriptive cross sectional study with quantitative and qualitative components. The qualitative and quantitative approaches complement each other in ascertaining project stakeholders views regarding project achievements, facilitators, challenges and lessons learnt. The quantitative component of the evaluation was limited to a review of project documents and the routine health facility reports to generate information on utilization of eMTCT and paediatric HIV services at target health facilities compared to baseline in 2017 and TAFU 2 endline conducted in 2019. The qualitative part of the study generated insights of project implementers and beneficiaries with regard to relevancy, most significant changes/achievements of the project, facilitators of success, challenges, lessons and suggestions to improve the effectiveness of similar projects in future and in other settings.

<sup>&</sup>lt;sup>1</sup> The National Forum of People Living with HIV/AIDS Networks in Uganda (NAFOPHANU) worked in all the intervention districts.

#### 2.3 Data Collection Methods

#### 2.3.1 Documentary Review

The study team conducted an extensive documents review. The review included key project documents such as the baseline report, project model document, annual and other project reports. This phase provided quantitative and qualitative evidence on project benefits, facilitators, challenges and lessons learnt during the TAFU program across study sites.

#### 2.3.2 Quantitative methods of data collection

a. Data abstraction from Health Facility Information Management System/Reports

The quantitative component of the study involved retrieval and analysis of data from all the 23 target health facilities in relation to number of children living with HIV on ART and women in eMTCT program. Data for this component of the study was obtained from TAFU partner and health facility reports.

In addition, a health facility check list was used to capture key health system indicators at all the 23 project health facilities at the end of the program compared to what was documented at the end of TAFU 2 in 2019. The key indicators for assessment were in relation to eMTCT and Paediatric HIV care including: availability of eMTCT, adult and paediatric ART services, staff trained on PMTCT and Paediatric HIV care, paediatric and Early Infant HIV Diagnosis, support groups for mothers/families in eMTCT and for children and adolescents living with HIV, linkages with communities for mobilisation and education on eMTCT and Paediatric HIV, linkages and involvement of People Living with HIV and having a system for referral, follow-up and tracing of pregnant HIV positive women and HIV positive children. The main outcome of this phase was quantitative status of eMTCT and Paediatric HIV services.

#### 2.3.3 Qualitative data collection methods

Qualitative and consultative methods of data collection were used with varied program stakeholders at program level (partners), district (DHT, PMTCT and HIV focal persons), Health Facility (Health workers involved in PMTCT and Paediatric HIV Care) and intended project beneficiaries. The main methods of qualitative data collection were Focus Group Discussions (FGDs), Key Informant Interviews (KIIs) and in-depth interviews (table 2). The focus of the qualitative data collection was to provide an in-depth understanding of stakeholders regarding TAFU program achievements, facilitators and challenges with regard to eMTCT and Paediatric HIV care at family, community and health facility levels in the target districts. Qualitative methods also helped appraise the most significant change of TAFU 3 interventions.

#### 2.3.4 Focus group discussions (FGDs)

These were conducted with mothers in the eMTCT programme, adolescents living with HIV, caregivers of children living with HIV, Networks of people living with HIV, Village Savings and Loan associations and Village Health Team members (VHTs) under TAFU. Overall, 5-8 FGDs per district - a total of 31 FGDs of 6-8 participants each were conducted with various project stakeholders (Table 2). On average, each FGD lasted for about 60 to 90 minutes and was conducted by two people, one as a facilitator and the other as a note taker. All FGDs were audio recorded and later transcribed.

#### 2.3.5 Key informant Interviews (KIIs)

Key informants deemed to have a broader understanding of the TAFU program and in position to appraise it in terms of effectiveness, most significant change, challenges, facilitators of success and lessons learnt were purposively selected to participate in the evaluation. Overall 8-10 key informants per district (total 43 KIIs) with district officials involved in eMTCT and Paediatric HIV

Care, Health workers, leaders of PLHIV networks, support groups, staff of partner agencies, community and religious leaders and staff of other programmes on eMTCT/Paediatric HIV were interviewed.

#### 2.3.6 In-depth Interviews (IDIs)

These were conducted with 5 mothers in the PMTCT programme and 6 adolescents living with HIV to generate narratives on project beneficiaries' experiences, perceptions, facilitators, challenges and suggestions for improving eMTCT and paediatric HIV services. IDIs also explored the most significant changes attributed to the project by the target groups and narratives of how the program functioned or failed to function in relation to the needs of the target population. In line with principles of qualitative research, data collection in each district continued until saturation was attained.

Table 2: Summary of Sample Size and Data Collection Methods for TAFU3 evaluation

Category/ Data collection Method		TAFU Program Evaluation					
		Mityana	Kyenjojo	Ntungam	Soroti	Total	
Quantitative methods - Health facility checklist to assess current status of eMTCT and Paediatric HIV services at intervention health facilities	4	5	4	4	6	23	
Qualitative methods							
In-depth interviews (IDI) with Adolescents and Young people living with HIV/their caregivers and mothers in eMTCT programme in project areas	4	1	2	2	2	11	
Key Informant Interviews (KIIs) –district officials involved in PMTCT and Paediatric HIV Care, Health workers, leaders of PLHIV networks, support groups, staff of partner agencies, community and religious leaders and staff of other programmes on eMTCT/Paediatric HIV	8	9	10	8	8	43	
Focus Group Discussions (FGDs) with mothers in eMTCT programme, Partners of women attending eMTCT, Children and adolescents living with HIV, caregivers of children living with HIV, Networks of people living with HIV and Village Health Team members (VHTs).	8	5	7	5	6	31	

#### 2.4 Data Analysis

To ensure quality of the data collected, the study team trained and supervised research assistants. Daily research team meetings were held at the end of each day of data collection to capture emerging issues. At the end of the data collection in each of the study districts, a research team meeting was conducted to capture their perspectives from the field regarding concerns of the study.

Qualitative data from in-depth interviews, focus group discussions and key informant interviews was analysed using content thematic approach. The process of qualitative data analysis involved reading interview and discussion scripts to identify themes and sub-themes which were used to group data for interpretation. Matrices and selected direct quotations from the discussions and interviews were used in the presentation of evaluation findings. Data analysis was informed by the Socio-Ecological Model (SEM) analytical framework (12-15) . SEM was selected to provide a basis for identifying facilitators and barriers to project implementation at individual, organizational (health facility and partner CSO) and community levels.

Quantitative data from health facility checklists and project reports was entered and analysed using excel to generate frequency tables. The main outcome measures were 1) number of children living with HIV enrolled in care 2) number and membership to VSLAs and 3) number of VHTs and CoRPs trained and supported. Overall, quantitative and qualitative evaluation findings were triangulated.

#### 2.5 Ethical consideration

Approval to conduct the study was obtained from the Joint Clinical Research Centre - Institutional Review Board/Research Ethics Committee (JCRC - IRB/REC). Permission to conduct the study was obtained from management of the study districts and health facilities. Consent/Assent were obtained from each of the study participants before conducting the interview or discussion. All adolescents who took part in the study, they provided assent and their guardians/parents provided consent. The purpose of the research was clearly explained to the different respondents and they were assured of confidentiality by the researcher or research assistant. Study participants who were found to require information, counselling and care were linked/referred to health facilities/health workers for further assessment and support. Research assistants fluent in English and the local languages spoken in the study areas were trained on the purpose, approach and ethical issues of the study and participated in the pre-test of study tools. The study team adhered to all Covid 19 standard operating procedures to ensure safety of both participants and researchers.

#### 2.6 Limitations of the Study

Challenging were the gaps in data at some health facilities and in partner reports on indicators such as women exposed, infants tested for HIV, children born free from HIV among HIV positive mothers, women and children lost to follow-up. While a comparative group outside the project setting would strengthen the study due to resource constraints conducting a sub-study was not possible. Inclusion of secondary quantitative data abstraction as well as primary qualitative data provided a basis for methods triangulation which enhanced evaluation findings. Some children and women supported by the TAFU program sought care from higher level health facilities and NGOs, these health care facilities were not included in the evaluation and such data was not captured by most program partners. Thus program reach is likely to be underestimated.

# 3 TAFU endline findings

#### 3.1 Introduction

In this section, findings of the TAFU program participatory evaluation are presented. Throughout the endline assessment, the evaluation team assessed the extent to which the program delivered on intended outcomes and the findings are presented in the sections following.

#### 3.1.1 Key TAFU Interventions and achievements.

The evaluation revealed that since 2015, TAFU program implemented interventions aimed at strengthening community systems and creating linkages between health care facilities and communities for paediatric HIV prevention and care. Partner CSOs together with district officials identified and built the capacity of VHTs and Community resources persons to serve as bridges between communities and health care facilities. The community structures identified pregnant and lactating women and referred them to health facilities for HIV testing. Those found to be living with HIV were enrolled into HIV care for themselves and for prevention of vertical transmission of HIV. The TAFU program also built the capacity of community resource persons/structures to trace, support, refer and follow-up children living with HIV and to increase community awareness on paediatric HIV prevention in areas where VHTs and CoRPs reside. The program mobilized caregivers of children living with HIV and supported them to form village savings and loan associations to address the socio-economic barriers they face such as stigma, poverty and limited knowledge on care for children living with HIV. At health facility level, the TAFU program, enhanced coordination mechanisms among VHTs/Community resource persons and health facilities for tracing, identification, care, referral and follow-up of children living with HIV. The program also supported partners to lobby and advocate for improved paediatric HIV prevention and care services in target areas.

The key achievements of TAFU are summarised in Table 3.

Table 3: Key TAFU 3 achievements

Indicator	TAFU 3
No. of household visits done by VHTs & CoRPs	16, 478
No. of children and Adolescents in care 0-19 at TAFU supported health facilities	1137
No. of children and Adolescents in care 0-19 at TAFU supported health facilities Virally suppressed in past 12 months	842
No. of children in care 0-14 at TAFU supported health facilities	771
No. of adolescents in care 15-19 at TAFU supported health facilities	366
Number of pregnant women referred for HIV testing, ANC and maternity services	5,532
Number of pregnant women referred for HIV testing, ANC and maternity services and completed referral	4989
Number of pregnant women referred for HIV testing, ANC and maternity services tested HIV positive and initiated on care	341
No. of children O-14 at TAFU supported health facilities referred for HIV testing	3,425
No. of children O-14 at TAFU supported health facilities referred for HIV testing & completed referral	2,880
No. of children O-14 at TAFU supported health facilities refered for HIV testing who tested HIV positive and initiated in care	46
No. of VHTs and CoRPs trained	670
No. of VHTs and CoRPs active at evaluation	657
No. of community VSLAs established/supported	48

No. of VSLAs for VHTs established/supported	21
No. of VSLA member beneficiaries	1442
No. of children benefiting from VSLAs (general)	1245
No. of children living with HIV benefiting from VSLAs	206
No of children living with HIV supported with ART delivery during COVID 19 restrictions	796
No of women living with HIV supported with ART delivery during COVID 19 restrictions	400

Some indicators varied between TAFU 2 and 3 thus comparisons among baseline, TAFU 1, TAFU 2 and TAFU 3 are not possible across all indicators but where possible this has been done in text under specific sections of the report.

# 3.2 Improve identification, initiation and retention of children living with HIV and pregnant mothers

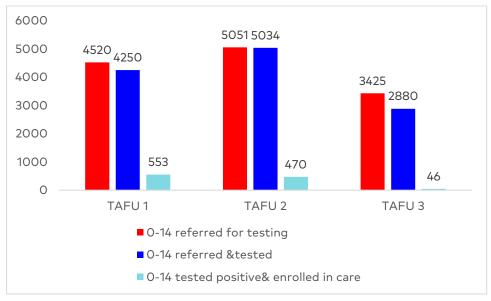
The evaluation findings revealed that TAFU program partners implemented activities at family, community and health facility levels geared at improving knowledge about paediatric HIV prevention and care, linkage and retention in care for children living with HIV as well as pregnant and lactating women living with HIV. The major activities undertaken to empower families of children and women living with HIV include: household visits, training and mentorship of VHTs and other community resource persons, joint VHT/CoRPs and health worker mentorship, community dialogue and sensitization meetings and targeted community outreach sessions.

#### 3.2.1 Train and mentor VHTs/CoRPs in paediatric HIV prevention and care

A total of 670 Village Health Team members (VHTs) and Community Resource Persons (CoRPs) were trained and mentored on paediatric HIV and eMTCT in TAFU 3 program areas (Mityana 43, Kyenjojo 44, Mubende 63, Ntungamo 80 and Soroti 440). In Soroti District, each of the 40 trained VHTs mentored 9-10 CoRPs in their communities which is higher than those mentored in other areas. This approach of assigning trained VHTs to mentor others in areas where they work and reside, is promising and can help to increase the number of community resource persons. However, discussions with mentored CoRPs revealed a need to supplement mentorship by trained VHTs with training and provision of reference materials to better equip CoRPs for their roles. During TAFU 3, the program worked with 300 VHTs trained during TAFU 2 to mentor other VHTs and CoRPs to improve their knowledge and skills regarding eMTCT and paediatric HIV care. In TAFU 1, the program trained and worked with 1,378 community resource persons. Quarterly and monthly mentorship sessions for VHTs/CoRPs were done jointly by TAFU partners and members of the District health teams. These meetings were credited by stakeholders for strengthening linkage and referral systems between communities and health centres; increasing treatment literacy and facilitating age-appropriate HIV disclosure. Health workers and VHTs noted that mentorship meetings had resulted into improved referral of women and children from community to the health centres and those who missed health facility visits to VHTs for follow-up.

Throughout the evaluation, VHTs and CoRPs were appreciated for conducting home visits, referring children and women to health facilities for HIV testing and care, conducting ART adherence counselling for mothers and children and tracing those who miss ART refill appointments for support. During the evaluation period, 3,425 children up to 14 years were referred for HIV testing at TAFU supported health facilities of whom 2,880 were tested and 46 of them found to be HIV positive were initiated in care. The findings of TAFU over the three phases regarding the number of children referred for HIV testing at target health centres, those tested and initiated in care are summarized in figure 2.

Figure 2: Number of children O-14 years referred, tested and initiated in HIV care during TAFU1-TAFU 3



For some women and children living with HIV who could not reach health facilities especially during COVID-19 restrictions, VHTs delivered ART at home thus promoting adherence. The VHTs and CoRPs also sensitized mothers to attend antenatal care to give birth at health facilities.

As VHTs, we follow-up on the health of the children living with HIV and educate women how to avoid producing children with the virus . ... (FGD VHTs Ntungamo).

When a child or mother doesn't turn up for clinic appointments, health workers call us and we look for them to bring them back to care. We follow-up and advise on ART adherence or send them for drug refills (FGD VHTs Soroti).

TAFU trained and mentored VHTs on paediatric HIV prevention and care. They educate community members to go for HIV testing especially pregnant women so that those found to be living with HIV start on ART for their own care and to prevent passing on HIV to their babies. They also identify

and refer children suspected or known to be living with HIV to the health facilities for care (District Official Mityana).

Community health workers encourage women not to deliver from villages by the traditional birth attendants but to go to health centres to prevent HIV to be transmitted to the baby. ... (FGD Caregivers of children LHIV, Kyenjojo).

The above narratives show that VHTs and other CoRPs in TAFU target communities serve as a mechanism for tracing and referring children and women to health care facilities for HIV testing and care; and were a source of information on paediatric HIV prevention and care. The VHTs and CoRPs are instrumental in the identification of pregnant women and educating them about antenatal care and giving birth from health facilities. As such the number of women attending ANC and giving birth at health facilities had increased.

In the past, we would have about 50 deliveries per month. We now have 80-100 deliveries per month. So sensitization by VHTs trained by TAFU for women to attend ANC and five birth at health centres has made a difference (HW, Ntungamo District).

Health care workers identify children lost to follow-up, those not adhering to treatment and those with unsuppressed viral load and share information with VHTs who conduct home visits to provide support including bringing them back to care. Throughout the evaluation, VHTs and CoRPs revealed that the training and mentorship they received empowered them to perform their roles much better than before. While the strategy of using trained VHTs to mentor others helped to increase the number of community resource persons with knowledge and skills on paediatric HIV prevention and care, most mentored community resource persons expressed a need for more training, provision of reference materials and other items such as gum boots, bicycles and bags for use in their work. Expression of these needs is a common reality in most community health worker programs and should be prioritized by government and partners to improve effectiveness of these programs.

Evaluation findings revealed that NAFOPHANU trained 20 sub-county networks of people living with HIV in the 5 target districts to promote ART literacy among women and children living with HIV and advocacy on issues affecting HIV care which further improved use and adherence to ART in target areas. The trained sub-county networks cascaded the information on ART literacy to parish and health facility based groups of people living with HIV. Overall, 466 people living with HIV were oriented on paediatric HIV and and advocacy skills. These are engaged in advocacy and awareness raising for paediatric HIV prevention and care in their areas. In addition, NAFOPHANU

conducted ART treatment literacy sessions for expert clients, mentor mothers and health workers in target areas. These reached a total of 864 (females 543 and 321males) individuals. As a result participants were empowered with knowledge about ART which improved treatment adherence for children and women living with HIV.

The major bottlenecks encountered in building and maintaining a functional network of VHTs and CoRPs were: the limited number of VHTs and CoRPs trained and the limited number of subcounties covered by the program in target districts. For instance in Ntungamo TAFU was implemented in 6 out of the 34 sub counties in the district. In Mubende the was implemented in 4 out of 19 sub counties, While health facility, sub-county and district officials appreciated the role of VHTs and CoRPs, limited financial resource hindered provision of support to these structures. While VHTs and CoRPs were involved in many activities at community and health facility levels, most of these activities were not documented.

#### **Emerging Issues/Lessons**

- The approach of trained VHTs mentoring other community resource persons on eMTCT and
  paediatric HIV increased the number of CoRPs. These however, expressed a need for more
  training, provision of reference materials and tools to aid their work especially promoting ART
  adherence and supporting disclosure of HIV status to children and family members.
- VHTs and other CoRPs increased identification and referral of women and children for HIV testing, care and support with ART adherence.
- TAFU strengthened working relationships between health facility staff and VHTs/CoRPs through training, referral, joint planning and review meetings. Health facility staff and VHTs/CoRPs positively appraised their collaboration and working relationship.
- Training of CoRPs and networks of people living with HIV on ART literacy improved their knowledge and skills to support people living with HIV to adhere to treatment.

## 3.2.2 Household visits to improve HIV prevention, testing and treatment for children and women

A review of project reports and interviews with project stakeholders revealed that as part of the TAFU program, village health teams (VHTs) and community resource persons including expert clients conducted 16.478 household vists. This includes household visits to families with children and women suspected or known to be living with HIV in their areas. During household visits information on the importance of HIV testing was provided and children or women living with HIV were counselled on ART adherence and elimination of mother to child transmission (eMTCT). Those suspected to be living with HIV were referred to health care centres for HIV counselling and testing. VHTs/CoRPs conducted follow-up visits to assess compliance with referral and need for additional support.

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Evaluation findings revealed that household visits conducted by VHTs and CoRPs as part of TAFU program helped to identify and refer women and children for HIV testing; and link those found to be living with HIV to care.

VHTs provide information on the importance of paediatric HIV and eMTCT services, remind clients to go for their follow-up appointments (District Official, Kyenjojo).

# Through the work of VHTs, 24 new children living with HIV were identified and enrolled in care (KII-Ntungamo)

What is emerging from the above narrative is that home visits by VHTs and CoRPs supported by TAFU enhanced identification of women and children living with HIV, referral and linkage to care. VHTs and CoRPs helped to address other community health promotion needs including immunization, malaria prevention and sanitation.

#### 3.2.3 Identify and refer children and women for HIV testing and care

The findings of the TAFU 3 endline revealed that all community activities including household visits, community outreach and dialogue meetings were aimed at raising awareness on HIV prevention, testing and enrolling and retaining children and women living with HIV in care. Targeted community outreach sessions were conducted to test children exposed or suspected to be living with HIV and those found HIV positive were linked to health facilities to enroll in care. The VHTs and CoRPs identified and re-engaged women and children who had dropped out of care.

A review of the TAFU program reports indicated that 1.137 children and adolescents living with HIV were in care at the health facilities engaging in the TAFU program (table 4).

Table 4: Number of children and adolescents on ART at target HCs by District at endline 2022

District	CLHIV 0-14	ALHIV 15-19	Total
Kyenjojo	195	82	277
Ntungamo	161	62	223
Mubende	172	118	290
Mityana	162	84	246
Soroti	81	20	101**
Total	771	366	1137

<sup>\*\*</sup>Some children living with HIV were in care at other agencies. For instance, 233 (0-14 years 165 and 15-19 years 68) in Soroti were served by other agencies including: SRRH, TASO, Uganda cares, Health facilities (HCIII) Others services (OVC): UWESO, SORUDA, AMECET Children's Home.

Evaluation findings indicate an increase in the number of children and adolescents in HIV care from 699 at baseline in 2017 to 1065 at the end of TAFU 2 in 2019 and to 1,137 at the end of TAFU 3. Taken together, an addition of 438 children and adolescents living with HIV were supported by the program to enrol or re-engage in care at target health facilities between 2017 and 2022.

For children and women in HIV care, household visits were used to assess adherence to treatment and provide support. In some instances, household visits were used to follow-up children and women living with HIV who missed clinic appointments or who were lost to follow up. Health

workers at the health facility identified the children and women who were lost to follow up and shared lists with VHTs and CoRPs for tracing, counselling and re-engaging with care.

The VHTs and community resource persons visit homes with children and mothers living with HIV especially those who miss clinic appointments and encourage them to come for care (Health Worker Ntungamo, District).

The VHTs have played an important role. They provide counselling at home and some times accompany children to health centres for care (District Official, Mubende, District).

During the COVID-19 pandemic and lockdowns, VHTs and CoRPs were credited for collecting and delivering ARVs to 796 children and 400 mothers living with HIV who were unable to reach health facilities. It was noted that VHTs had been trained and were involved in childhood vaccination, sanitation promotion and in handling cases of gender based violence.

# Communities now know that we go to communities for different reasons such as immunization, sanitation and hygiene as well as gender based violence prevention... (FGD VHT Kyenjojo, District)

In line with the test and start ART policy of Uganda, children and adults living with HIV are initiated on ART rightafter diagnosis. The endline survey revealed that all children in care at target health facilities were on ART. Over the past four years, the TAFU program trained and mentored health care workers at health facilities on paedatric HIV and advocated for identification of children living with HIV, initiating and retaining them in care thus contibuting to the increased number of children living with HIV in HIV care.

It should be noted that VHTs and CoRPs also visited and supported children and women living with HIV who receive care from higher level health facilities and agencies. For instance, in Soroti, district, 233 children living with HIV who were supported by TAFU VHTs and CoRPs were receiving care and support from other agencies and facilities such as TASO, Uganda cares and other health facilities. In Ntungamo District some children and women living with HIV were receiving care from TASO in Mbarara. In Mubende, Kyenjojo and Mityana districts some children and women living with HIV were enrolled in care at district hospitals. Despite that these children and women living with HIV were enrolled in care, they are not reflected in the TAFU data because of enrolment in care in other health facilities. The actual program reach and achievements, including the number of children supported by VHTs, is therefore higher than documented.

The activities contributed to finding and enrolling children and adolescents living with HIV in care as well as retention of those already in care. All key informants and FGD participants across study districts highligted the role of VHTs and CoRPs in linking children and women to HIV care as well as

retaining those in care through home visits in which they provided education on paediatric HIV, cousnselling and mediation to enhace adhrence as some participants explained.

Because of increased awareness through activities of VHTs many children have been brought on board and are educated on how to live with HIV (FGD VHT, Kyenjojo)

TAFU has trained VHTs on counseling and guidance and they have guided us on how we should behave, we used to throw our drugs away and lie that we have swallowed them. This mentality has changed due to constant education by VHTs which has increased viral suppression (FGD children Kyenjojo).

TAFU program has increased awareness about paediatric HIV care and PTMTC in communities. It has helped to link health workers and VHTs, they all work together to find chidren living with HIV, enroll them in care and ensure they are retained (District official Soroti).

Evaluation findings also revealed that some of the children enrolled in care were lost to follow up or missed clinic appointments which has a bearing on ART adherence and viral suppression. As such health workers in collaboration with VHTs and CoRPs traced and re-enrolled them in care.

The VHTs help to follow-up on children and adolescents who do not turn up at the clinic. They do home visits and encourage clients to return to care and to adhere to ART (HW, Ntungamo District).

Children who are lost to follow-up and those who miss clinic appointments, the VHTs under TAFU get lists from health centres, conduct home visits and bring them back to care...(HW Soroti District).

What is emerging from the above narratives is the fact that TAFU has strengthened follow-up and support mechanisms for children living with HIV and conributed to retention in care.

Regarding eMTCT, the TAFU program enhanced women's utilisation of antenatal and maternity care, HIV testing and linkage to eMTCT program. Overall 5,532 pregnant and lactating women were referred by VHTs and CoRPs for ANC, HIV testing and maternity services of whom over 90% completed referral. Those who tested HIV positive (341) were enrolled in HIV care for their own health and for prevention of mother to child transmission of HIV.

A major achievement of the TAFU program acknowledged by most stakeholders is that the majority of HIV positive women in the eMTCT program gave birth to HIV negative children.

TAFU contributed to the success of our eMTCT programme. Most mothers living with HIV these days give birth to HIV negative babies and that motivates VHTs and health workers to keep working and educating communities (HW, Ntungamo District).

All our HIV exposed babies are HIV negative. This is because the VHTs and health workers support mothers to attend ANC, adhere to ARVs and give birth at the health facility (HW, Soroti District).

I can say the performance of our eMTCT program is good. We initiate all mothers who test HIV positive on ARVs and get HIV negative babies. I can say our performance is 9/10. The few children who turn HIV positive are from mothers who are not in the eMTCT program (HW, Kyenjojo District).

Most children produced by mothers in care are HIV negative and this is very good for us as VHTs (VHT, MityanaDistrict).

#### Emerging Issues/Lessons

- Household visits by VHTs and community resource persons helped to identify and refer women and children for HIV testing, and to link women and children living with HIV to care
- Through home visits, VHTs and CoRPs supported caregivers of children with the information needed to care for children living with HIV. This information includes nutrition and atreatment adherence.
- TAFU interventions at health facility and community level increased the visibility of paediatric HIV which resulted in prioritising children for HIV testing and care at target HCs.
- TAFU enhanced follow-up and support systems for children and adolescents living with HIV thus improving retention in care.
- Most HIV exposed children in TAFU intervention areas test HIV negative which implies that TAFU works and it motivates VHTs and health workers to continue with community mobilisation and education activities

#### 3.2.4 Family economic strengthening through VSLAs to better care for children

Evaluation findings revealed that the TAFU program partners facilitated mentorship and support to 69 Village Savings and Loan Associations (VSLAs) (48 community VSLAs and 21 VSLAs for VHTs/CoRPs). Through the VSLAs 1,442 members have benefitted These groups directly supported 1,245 children of whom 206 (17%) are living with HIV. The majority of the VSLAs had been registered with District Local Governments which provided additional guidance to groups and financial support. The distribution of VSLAs by district is summarised in table 5.

Table 5: Ke	y VSLA achievements under TAFU 3 by	y district

Partner	No Community VSLAs	No. VSLA members	No of Children Behind VSLAs*	No of CLHIV with caregivers in VSLAs
Ntungamo	10	249	88	88
Kyenjojo	9	273	141	141
Mubende	9	333	144	144
Soroti	11	394	666	31
Mityana	9	193	206	202
Total	48	1442	1245	206

\*In Ntungamo, Kyenjojo and Mubende District reports only the captured number of children living with HIV under caregivers in VSLAs not the general number of children.

The VSLA groups were trained on roles and responsibilities of members, leadership, savings mobilisation, loan management, income generating activities, record keeping and linkages with other actors especially local government to elicit additional support. Linkages with the health system and community structures such as village health teams and other community resource persons were also emphasized for the care of children and adolescents living with HIV. Groups were supported with VSLA kits (stamps, books, pens, savings box and individual books) and seed funding of 400,000-500,000 (USD 108-135) to boost group funds for loaning to members. Members save 500-1,000 Uganda shillings (0.13 -0.3 USD) as social fund which members borrow to meet health care needs of their children living with HIV or their own health needs and re-pay it without interest. Individual members save 1000-10,000 Uganda Shillings (0.3 – 3 USD) monthly and take loans of 10,000 - 500,000 (2.7- 135 USD) depending on group capacity and members needs. Loans are re-paid with an interest of 5-10%.

TAFU partners together with district officials especially community development officers conducted joint group supervision meetings to further enhance the capacity of VSLAs including

support to register with local governments. Evaluation findings indicated that most VSLA members had started income generation activities such as crop farming, poultry, goat rearing, piggery, and market stalls. Caregivers were also encouraged to start vegetable kitchen gardens, although at the time of the evaluation these were more available among caregivers in Ntungamo District.

During VSLA meetings, members were educated on positive living and they shared experiences and challenges faced including non-adherence to ART and HIV related stigma and received guidance and support. Across all TAFU areas, VSLA members and other stakeholders appreciated VSLAs for saving and borrowing funds which enables them to start income generating activities. This helped them to meet the basic needs of their families especially in relation to health, food and education. Most caregivers of children in VSLAs, mentioned that they had borrowed money for transport to take children under their care to health facilities for follow-up visits and ART drug refills or for themselves. Others had used the money to buy medicines for opportunistic infections not provided at health facilities. Similarly, most key informants across study areas cherished VSLAs for enabling caregivers of children to meet the needs of children living with HIV under their care.

I borrowed money from my group and started selling dry fish. This has enabled me to pay school fees for children under my care including one in secondary school (Caregiver, Kyenjojo District).

Because of joining the VSLA, my children now have a balanced diet unlike before, Health Need [Uganda] came when children were malnourished... (Caregiver, Soroti District).

Since most caregivers are now in VSLAs, they are able to raise transport to take the children to health facilities (FGD VHT, Mubende District).

The VSLA groups had also resulted in members developing strong bonds which were a basis for psychological and material support. The VSLA groups were a source of information on PMTCT and paediatric HIV.

We have become like relatives. We help each other. For example one of our members was involved in an accident and we supported her to get care ..(FGD caregivers, Mityana District).

The VHTs encouraged me to join VSLA where I met other caregivers and their children were looking healthy, I got motivated to care for my child better. In the group, I found other caregivers, we share and laugh and I have learnt a lot on how to care for my child. I got a loan of 50,000/- and started selling vegetables in the market. I pay school fees for my child, I no longer lack money to take him to hospital (Caregiver, Mubende District).

The VSLAs have helped us to spread the message about prevention of mother to child transmission of HIV and paediatric HIV care. We visit our friends in homes, share information and guidance each other (FGD PHA Network, Mityana).

VSLA meetings for caregivers were linked with peer support for caregivers and children. Issues such as disclosure and improving care for children were discussed and those requiring more support were identified and linked to counsellors (KII Ntungamo District).

Through the VSLA group meetings, I realized I am not the only one with a child living with HIV others have more than one child. This realization helped me to overcome fear and continue supporting my child to take her drugs (ARVs). ARISE has strengthened my capacity in fighting stigma. Currently I love myself and my child... (Caregiver, Ntungamo)

What is emerging from these narratives is that VSLAs improved the capacity of caregivers of children living with HIV to meet their own needs and those of their families through providing affordable credit facilities, starting income generating activities, providing information on self-care and care for children as well as psychosocial and material support for caregivers. In addition, VSLA groups provided platforms to raise community awareness on eMTCT and paediatric HIV care thus

improving HIV and treatment literacy. The VSLA groups helped caregivers to feel supported, they were strengthened by the feeling that they were not on their own and were, motivated to care for themselves and their children.

Due to linkages and registration with district local governments, some VSLAs had received grants/loans from government programmes. For instance two groups in Mubende and four groups in Ntungamo had received financial support from Government programmes such as Emyoga and Uganda Women Entrepreneurship Program (UWEP). Each group in Ntungamo received 8 million Uganda shillings (2160 USD) which boosted their possibilities to provide loans to members and start or expand income generating activities. However, some groups were apprehensive on applying for government loans due to fear of repayment challenges and opted to rely on the available group funds. The number of community VSLA groups and members across the three phases of TAFU are summarized in figure 3.

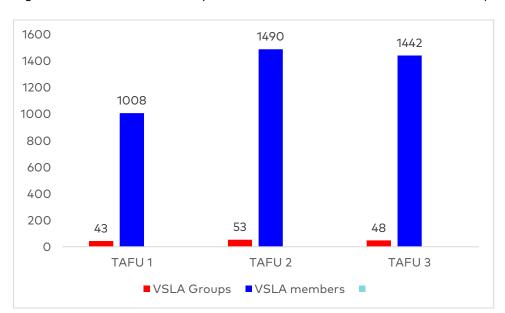


Figure 3: Number of community VSLAs and members across the three TAFU phases

#### 3.2.5 VSLAs for VHTs and Communty Resource Persons

Overall, the TAFU project supported the formation of 21 VSLAs for VHTs and CoRPs in the five intervention districts (3 in Ntungamo, 4 each in Mityana, Mubende and Kyenjojo and 6 in Soroti) during TAFU 3. In Soroti District, 4 VSLAs were established in TAFU 2 and continued to receive support in TAFU 3. On average each VSLA had 15-30 members. Members of these VSLAs were trained on group management, savings and credit, development of rules and regulations, leadership, record keeping and income generation to sustain their activities. The VSLAs received a savings toolkit including savings boxes, padlocks, saving books and record books. The training events were conducted by TAFU partner staff together with district based VSLA trainers, health educators and community development officers. The involvement of district officials in training VSLAs was intended to ensure continuity of support beyond TAFU project.

All VSLA groups received mentorship support from TAFU partner staff, health workers and community development officers on group management, conduct of meetings, savings and credit as well as record keeping. Mentorship was integrated in monthly VSLA/VHT meetings held at health facilities.

Evaluation findings revealed that VSLAs for VHTs were appreciated across all TAFU districts as an opportunity to sustain this important structure. Indeed VHTs and CoRPs applauded their VSLAs

for providing opportunities for them to continue meeting, sharing experiences and continue learning from each other. At the same time it helped them to borrow funds for income generation activities and to meet their individual and family economic needs. Support from VSLAs was a source of motivation for VHTs and most of them mentioned these groups as likely to encourage them to continue with community work even beyond TAFU program. It was noted that VHTs meet monthly at health centres to share experiences, provide feedback to health facilities, save and take or re-pay loans. At some health facilities, health workers had joined VSLAs for VHTs which had strengthened the collaboration between VHTs and health workers.

This phase of TAFU, we supported VHTs to start their own VSLAs which has increased their motivation. Savings and loan activities are integrated in their monthly meetings held at health facilities (KII Soroti District).

VSLAs have empowered us so, even when TAFU project ends we can sustain ourselves financially through the savings and credit schemes (FGD VHTs, Kyenjojo).

In the past, VSLAs were only for community members. This time, we were supported to form our own savings and loan associations as VHTs which is good. We also have an opportunity to develop ourselves and our families so we can work with one heart (FGD VHT Ntungamo)

In Soroti District, VHTs were supported to start family projects such as goat rearing, poultry, piggery and crop farming. These further increased motivation of VHTs.

In the past all support went to the people we serve. But this time we are happy that HNU thought about us. For me when I see the goat I received from TAFU it encourages me to do more work in my community (FGD VHTs, Soroti).

Among the major gaps noted regarding VSLAs was limited financial resources to meet the loan needs of group members, poverty that resulted into low savings and disruptions of businesses due to COVID-19 and related restrictions. In all TAFU districts, many cases of businesses which had collapsed during the COVID-19outbreak were reported. This was mainly due to closure of businesses during lockdown periods and drawing on savings and capital for family sustenance.

Access to food was a challenge, those with small businesses were told to stay home, so it was hard to save or repay the loans (KII Soroti District).

Many people who had started businesses like market stalls made losses during lock downs due to Covid 19 and could no longer save and those that had received loans they could not pay. It was a huge challenge as people struggled to survive. You could not tell them save when they needed food (KII Mubende District).

Poverty is the main challenge and it has increased due to COVID-19. So it is difficult to find money to save and when savings are low we do not have money to lend to members (FGD caregivers Kyenjojo District).

#### Emerging Issues/Lessons

- VSLA groups have helped caregivers to meet the needs of children living with HIV and their families particularly transport costs to health facilities, food and school fees.
- VSLAs provided safe space for psychological support to caregivers and children living with HIV through experience sharing, education and guidance on addressing challenges they face.
- VSLA groups for VHTs are a source of motivation for VHTs and present an opportunity for sustainability of VHT activities beyond TAFU Program.
- Monthly VSLA meetings for VHTs held at health facilities provided space for VHT-health worker interaction regarding care for children living with HIV.
- Poverty and disruptions due to COVID-19 were key challenges that constrained the role of community VSLAs.
- While TAFU supported VSLAs to register with district local governments, groups need to renew their registration annually which is costly.

#### 3.2.6 Empower Children living with HIV to adhere to treatment

Evaluation findings revealed that as part of the caregiver VSLA groups, discussions were held with children living with HIV to support them address the key challenges children and adolescents living with HIV faced. These discussions were facilitated by VHTs and TAFU partner staff. Some of the key issues discussed include; stigma, lack of food and side effects of ARVs. Concerns of children living with HIV about caregivers were discussed in caregiver meetings while those related to the health system were communicated to health workers.

During clinic days, health workers and peer counsellors (YAPS) conducted health education talks and counselling sessions to increase awareness of children, adolescents and their caregivers about ART, the need for adherence, disclosure and nutritional support for children and adolescents living with HIV for better outcomes. It was noted that these support activities for children and adolescents increased their confidence to adhere to ARVs. Repeated viral load testing were also a basis to motivate children and caregivers to improve adherence. Home visits by health workers and VHTs were also used to empower children and adolescents living with HIV to adhere to ART.

For me my granddaughter's condition was not good at all. The counsellor and VHTs looked for me and called me continuously on phone to know why the child was not coming to the health facility. The health workers took a lot of interest in the child. Every time we would go for drug refills, they would call me and tell me the viral load results are bad. They counselled me and counselled the girl as well until the child got well. I am very grateful to the health workers and VHTs because they have done a very good job. Now the child is fine and she knows why she is taking the drugs (Caregiver Mityana District).

Most health facilities had specific clinic days for children and adolescents living with HIV separate from those for adults. During these clinic days, children and adolescents are health educated, counselled, receive drug and are guided on how to address the challenges they face.

Every Tuesday we have a clinic for children living with HIV. Those due for viral load check, blood samples are collected, they are counselled and given ARVs in their own space ( HW Rubare HC IV, Ntungamo).

Central among the support team were the peers who drew on own experience living with HIV to guide and motivate others.

We have peers who support us in counselling and following up of adolescents and young people especially those who miss clinic appointments and do not adhere to treatment. Peers are also living

# with HIV and guide others based on their own experiences (District Official Mubende)

Children in FGDs and IDIs noted that support group meetings and counselling sessions by health workers, peers and VHTs had helped them to know why they were taking ARVs and were guided on how to address stigma. Children also appreciated the interaction with fellow children living with HIV which helped them to come to terms with HIV diagnosis and feeling they are not alone.

When we come to pick ARVs, we meet other children living with HIV which makes us feel we are not alone. Most health workers are good and guide us on how to take our drugs to remain healthy (FGD children, Kyenjojo District).

The VHT is my friend and has helped me a lot. When I have misunderstandings with my father, the VHT helps us to solve the differences. The counselor also talks to us and I get encouraged to take my drugs...(IDI Male Adolescent Ntungamo District).

Taken together, peer support meetings, clinics for children and adolescents and support from health workers and community resource persons were instrumental in helping children and adolescents living with HIV to overcome feeling they are the only ones living with HIV and empowered them to adhere to ART. Some children had been linked to other agencies which provided additional support. For instance in Ntungamo, TPO Uganda supported 17 children to attend apprenticeship skills in mechanics and carpentry. At the time of the evaluation most children were still undergoing training while a few had completed and were already earning income.

### **Emerging Issues/Lessons**

- Group meetings and special clinic days were a source of psychosocial support for children and adolescents living with HIV and their caregivers. They helped individual children and caregivers to overcome feeling they are the only ones living with HIV.
- Peers, VHTs and health workers were an instrumental source of support for children and adolescents to remain in care. Peers and VHTs who doubled as expert clients drew on personal experiences to support others.

## 3.3 Community education and dialogue meetings to increase awareness for eMTCT and paediatric HIV care

The evaluation established that the TAFU partners, VHTS, CoRPs, health workers and District health teams conducted community dialogue and sensitization meetings in all the target districts. During these meetings issues affecting care for children and women living with HIV at family, community and health facility levels were discussed and needed actions agreed upon. Some of the

issues discussed include: the importance of testing children for HIV, the challenge of HIV stigma and how to address it, the need for HIV disclosure, ART adherence and the need to increase male partner involvement for eMTCT and better care for children living with HIV. Community dialogue meetings were also used to raise awareness on paediatric HIV and eMTCT.

During the COVID-19 out break, challenges related to stigma and discrimination, HIV status non-disclosure, gender based violence, the high cost of transport to health facilities and shortage of food were common in all the five intervention districts. The number of community dialogue meetings varied across districts. For instance in Ntungamo, 103 community dialogue meetings were conducted with a total attendance of 2,539 community members while in Mityana District, 24 dialogue sessions were conducted with an attendance of 414 community members. The main outcomes of community dialogue meetings were increased awareness about eMTCT and paediatric HIV, increased number of women attending antenatal care and those giving birth at health facilities.

### 3.3.1 Coordination meetings between health workers and VHTs

The TAFU program supported monthly coordination meetings between VHTs/CoRPs and health care workers. During these meetings issues affecting eMTCT and paediatric HIV care were discussed and action plans generated. Some of the key issues discussed include: stock out of ART and other drugs for opportunistic infections, adherence and shortage of food as a major challenge to ART adherence. One of the major outcomes of these meetings was re-distribution of ARVs and HIV test kits. These were redistributed from health facilities that were well stocked to health facilities that experienced stock-outs and shortages. As a response to adherence challenges, NAFOPHANU conducted training sessions on ART literacy for caregivers of children living with HIV and for members of the sub-county and district networks. Joint meetings were also a source of advocacy issues which were often communicated to district officials, the Network of People Living with HIV, HIV implementing partners and the Ministry of Health for action.

Owing to the continued advocacy and lobbying by NAFOPHANU on the need to improve ART treatment literacy, PEPFAR through Ministry of Health (AIDS Control Programme) supported NAFOPHANU with USD 200,000 to support treatment literacy activities among children, caretakers of children and adolescents in the Acholi and West Nile regions. In addition, NAFOPHANU together with other CSOs monitored and reported regularly on the availability of ART especially for children. These reports were used to engage with the Ministry of Health, Clinton Health Access Initiative (CHAI), National Medical Stores (NMS) and other partners to ensure constant availability of ARVs including for children.

### Emerging Issues/Lessons

- Dialogue meetings, health talks during community outreach sessions and treatment literacy sessions increased awareness about eMTCT and paediatric HIV care and increased the visibility of issues requiring action by district, sub-county and health facility leaders.
- TAFU community activities enhanced caretaker knowledge on care for children and women living with HIV.
- Coordination meetings provided a regular space for VHTs and health workers to identify and address issues affecting use of eMTCT and paediatric HIV care and generated advocacy issues for action by district and national stakeholders.
- Lobbying and advocacy activities by NAFOPHANU with the ministry of health and other stakeholders at district and national level increased visibility and attention on gaps in paediatric HIV prevention and treatment.

### 3.4 Effects of COVID-19 and responses

The evaluation revealed that COVID-19 outbreak and related lock downs in TAFU intervention areas like the rest of Uganda compounded health access challenges for vulnerable groups especially children and women living. COVID-19 led to disruptions in public transport system making it difficult for children living with HIV and their caregivers to access health facilities for drug refills and to sustain ART adherence. In addition, HIV related stigma, gender based violence and shortage of food also increased amidst the fear of contracting COVID-19 which further constrained health facility visits. Also the lockdowns led to many families losing their sources of income which increased poverty, a major constraint to health service utilization. At program level, the 22 months school closure in Uganda hindered the implementation of school interventions.

Aidsfonds and partners in Uganda developed and implemented emergency COVID-19 response projects to address these challenges. As part of these projects, 200 VHTs and community resource persons and 100 expert clients across the five intervention districts were trained on COVID-19 prevention, provided with protective equipment and linked to health facility based health workers to identify children and women living with HIV that miss drug refill appointments and deliver ARVs at home. Overall VHTs, CoRPs and expert clients conducted home visits and delivered ARVs to 796 children and 400 women living with HIV on the program for prevention of mother-to child transmission of HIV. As such, the COVID-19 response projects contributed towards sustaining ARV refills and thus promoting adherence.

Transportation challenges and restrictions limited access to care. As a response, health facilities adopted provision of multi-month ART refills and some people living with HIV including children who were receiving ARVs from higher level care centres received refills from nearby health facilities. Home ART deliveries by VHTs, CoRPs and health workers further sustained ART delivery to children, women and men who missed clinic visits. However, both health care workers and community resource persons had to find ways of navigating the challenges of non-HIV status disclosure and the fear of stigma at household and community levels. In some instances, caregivers met ART distributers at public places near home such as schools, churches or trading centres agreed upon on phone prior to the visit. Health workers and VHTs avoided any potential identifiers linked to HIV care such as uniforms, branded t-shirts or bags during community ART visits. The implication here is that, implementers of community HIV programs such as TAFU need to intensify and sustain activities that facilitate HIV status disclosure and stigma reduction at family and community levels.

As a response to the food challenge, vulnerable children living with HIV and their caregivers were provided with food support which was appreciated. In Ntungamo District, caregivers trained on agronomic skills and provided with seeds for vegetable and fruit growing which further enhanced family food production capacity. It is important for HIV implementers to implement interventions to ensure sustainable food security as part of HIV prevention and care programs. Regarding the impact of the COVID-19 response interventions one caregiver explained:

Because of COVID-19, movements were restricted, so I could not move to the market to run my business. I was selling fruits and the ones I had bought got spoilt. So I later closed the market stall.

I lost my source of income and food for my family. During that time transport to the health centre was very expensive, it doubled. When my drugs and those for my child got finished I could not go to the health centre to get more. We spent some days without taking ARVs yet I knew we were not supposed to miss drugs. I became stressed and feared that we were going to die. After like a week, health workers called me and I directed them and they brought drugs home. Our VHT also brought us food. Although it was posho and beans which we do not usually eat, it was a big relief. Then the staff of Arise brought us seeds to grow our own vegetables, these ones we are still eating them (Caregiver of a child living with HIV, Ntungamo).

Across all the TAFU intervention districts partners provided protective equipment to VHTs, CoRPs and health workers such as face masks, gloves and hand sanitizers; and education on COVID-19 prevention as they interfaced with clients.

While COVID-19 and related lockdown restrictions hampered access to facility-based HIV services for children and women living with HIV, facilitating community-health facility linkages with community health workers and HIV expert clients at the centre enabled women and children living with HIV in all the five TAFU intervention districts to sustain ART drug refills and enhanced adherence. These findings demonstrate a need for HIV implementers, government and donors to invest more in building linkages between the community and health facility for resilient health systems to better meet the needs of the most vulnerable members of communities including children especially in times of disasters and outbreaks.

### **Emerging issues**

- COVID-19 and related restrictions increased barriers to paediatric HIV care and prevention.
   Major barriers were: disruptions in public transport system and loss of income for families
   which made it difficult for children living with HIV and their caregivers to access health
   facilities for drug refills and gender based violence response services.
- Home delivery of ARVs by VHTs, CoRPs, expert clients and health workers was a critical
  intervention that supported children living with HIV and their caregivers to remain in care and
  adhere to ART. However, ART distributers had to navigate the enduring challenges of none
  HIV disclosure and the fear of stigma among caregivers of children and women living with
  HIV.
- Provision of emergency food supplies was timely in meeting the immediate nutrition needs of vulnerable households. However, food supplies are costly, not sustainable and inadequate to reach all vulnerable households. Thus, implementers of community health and HIV programs like TAFU should include sustainable food security interventions in their programs.

### 3.5 Evidence for the TAFU model

The evaluation revealed that the TAFU program partners continuously shared lessons learnt from the program and lobbied stakeholders at health facility, community and district levels to address the challenges in paediatric HIV prevention and care.

At TAFU program partner level, six monthly partner meetings were held to review progress and share lessons learnt.

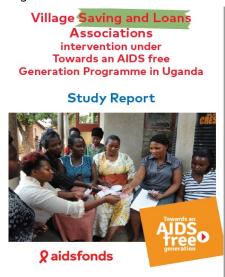
At health facility and district levels, dialogue and program review meetings were used to share updates on TAFU program, achievements, challenges, lessons learnt and actions needed to strengthen paediatric HIV prevention and care. These events involved health workers, community resource persons, district officials from departments of health, education and community development; non-government organisations implementing HIV activities and networks of people living with HIV. Networks of people living with HIV continuously monitored availability of ARVs and test kits and advocated for action to address identified gaps.

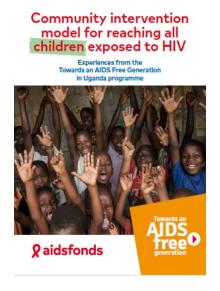
During the COVID-19 pandemic and related restrictions on transport, TAFU partners and networks of people living with HIV were instrumental in advocating for access to health services and facilities by people living with HIV. They lobbied for example for drug refills and supporting health care workers to provide health facility based and outreach HIV services as well as addressing challenges of HIV stigma, domestic violence and shortage of food especially among women and children living with HIV.

In all districts, quarterly information sharing meetings and joint support supervision meetings involving TAFU partners, health workers and district health teams were held to enable stakeholders review progress, challenges and emerging lessons. These meetings increased the visibility of paediatric HIV and the contribution of TAFU in target districts. Areas for linkage and collaboration among HIV implementing partners and TAFU partners within TAFU intervention districts were identified and partnerships established. For instance, in Ntumgamo District, TPO Uganda supported 17 vulnerable children to access skills training. In all districts, VSLAs were linked to the department of community development which increased access to additional support for group registration, capacity building and financial services.

The TAFU Model and the Village Saving and Loans Associations intervention documents developed under TAFU (figure 2) continued to be shared with stakeholders.

Figure 4: VSLA and TAFU Model Documents





Aidsfonds and TAFU partner organizations continued to monitor implementation and document outcomes of the program. Lessons learnt were continuously shared by partners with District HIV implementation stakeholders in target districts. In addition, two presentations were made at the recent international AIDS conference 2022 in Canada. During the COVID-19 epidemic, The National Forum of People Living with HIV in Uganda (NAFOPHANU) used lessons from TAFU to heighten advocacy on the concerns of people living with HIV including the need to sustain ART refills in times of lockdowns and food support. Aidsfonds and partners in Uganda, Nigeria, South Africa and Zimbabwe documented and shared lessons from the COVID-19 emergency response fund projects. These reports show continued community support of children with HIV in times of COVID-19. For wider adoption of the TAFU model, Aidsfonds and TAFU partners should engage in advocacy and continue sharing of lessons learnt from implementing the TAFU model with stakeholders involved in paediatric HIV and community health system strengthening. This is important to increase funding for such programs in Uganda and other similar settings.

#### **Emerging issues**

- TAFU partners continued to share lessons learnt and best practices from the program with district stakeholders. This increased interest in the TAFU model at district level.
- Aidsfonds and partners continued to share the TAFU model in Uganda and other settings.
- Aidsfonds needs to engage more in higher level advocacy with donors involved in paediatric HIV programming to increase chances of adopting and scaling up use of the TAFU model and increase resources for community system strengthening interventions.

### 3.6 Appraisal of the most significant contribution of the TAFU Program

Study participants were asked to mention the most significant change attributed to the TAFU program. Most study participants mentioned that the program increased community awareness about prevention of vertical transmission of HIV and paediatric HIV care. Training and working with VHTs and CoRPs increased identification, enrolment and retention of children living with HIV in care. The VHTs and CoRPs conducted health education, home visits, mobilisation and referral of women and children to health care facilities. During the COVID-19 outbreak, VHTs and CoRPs were credited for conducting health education about COVID-19 prevention. During the COVID-19 period VHT's and CoRPs were crucial in ensuring access to ART drug refill for many women and children who could not access health facilities due to the high transport costs and restrictions on movement.

Study findings also revealed that through community mobilisation, dialogue and sensitization, the TAFU program increased the demand for maternal and child health services in target communities. As such ANC attendance, delivery at health facilities and utilisation of HIV testing and eMTCT services had increased. All stakeholders in the evaluation including most mothers in the eMTCT program, health workers, VHTs and district officials highlighted women giving birth to HIV negative babies as one of the most significant changes attributed to TAFU.

More children have been brought on board and have been educated on how to live with HIV and grow like any other children. Also HIV transmission from mother to child has greatly reduced almost to zero (FGD VHTs, Kyenjonjo).

TAFU activities like communinity dialogues, HIV testing in communities and training VHTs have made many people aware of these services and encouraged pregnant women to test and those found with HIV to start treatment and save their babies. Many of us have given birth to HIV negative children and we are healthy (FGD caregivers, Mubende).

Across all study districts, participants mentioned that TAFU had helped to identify children who were living with HIV, enrolled them in care and supported retention in care and adherence to ART.

VHTs/CoRPs reached out to communities and more children have been enrolled in care and those who were lost to follow-up were traced and brought back to care (Health worker, Ntungamo).

Home visits and encouragement by VHTs under TAFU have helped many children and adolescents to adhere to treatment (PHA Mityana District).

TAFU has helped to empower community resource persons who have identified children living with HIV, linked them and supported them to remain in care. Initially, VHTs were known for childhood illnesses but TAFU has trained them to address HIV prevention and care for children. (District Official, Soroti).

In addition, it was noted that TAFU strengthened collaboration between health workers and VHTs for the benefit of women and children. It was noted that health workers and VHTs share information during joint review meetings or by phone regarding children and women especially those who miss their clinic appointments or other support. VHTs conducted home visits and provided feedback to health care workers.

We have the telephone numbers of all VTHs, so when a child or mother misses appointment, we call the VHT who visits the home to find out what happened. Some forget the appointment dates and are reminded by VHTs to come to the health facilty. Those who lack transport, some times we send VHTs in their areas to take for them ARVs for some time... (Health Worker Ntungamo District).

Initiation and support of VSLA groups for women and caregivers of children living with HIV was another significant change mentioned across all the program areas. Through VSLAs, caregivers borrowed money to cater for family needs including taking children to hospital, pay school fees and buy food. Some caregivers had started income generation activities which improved their ability to meet household need. The impact of the VSLA reached beyond the economic opportunities. Due to the possibility to earn income, caregivers were able to meet the nutritional needs of themselves and their children. In addition, the funds improved health outcomes.

I was given money to begin a business and I started selling fish. I have a constant flow of food at home for the children and myself. Due to this business the children have been able to eat a balanced diet, which is different from when Health Need had just come when they were malnourished and looking very bad. This business has also helped me to save in our group and this money helps to get transport to hospital and to buy drugs for children (IDI Caregiver Soroti).

Starting VSLAs is the major change. Parents go and get money which is for medical and they pay boda bodas to take us to hospital. My mother went to the group and got money which she used to buy a hen and that hen produced and we got goats and they have been used for school fees (FGD children LHIV, Mubende District).

TAFU educated and guided our parents and guardians to start VSLAs where they are able to get money for transport fares when we are going to health centers for drugs (FGD children Kyenjojo District).

Creation of VSLAs for sustainability, previously the clients used to cry over transport when coming to the facility most especially during Covid19 era and since they started saving little money they get some transport and they can now even buy food for their children (HW, Mityana District).

### 3.7 Relationship between the TAFU program and HIV interventions of stakeholders

The evaluation team sought stakeholders' perspectives on how the TAFU program related to other HIV programs in the intervention districts implemented by other organisations. While organisations such as Baylor Uganda in Kyenjojo, TASO in Soroti and Mildmay Uganda in Mityana and Mubende were responsible for general HIV programming and health system strengthening, the TAFU program served a niche. TAFU focused specifically on children living with HIV and facilitating linkages between communities and health facilities. VHTs, CoRPs, health care workers and district officials in this evaluation acknowledges the complimentary role TAFU played with its focus on children living with HIV.

The VHTs and CoRPs recruited and facilitated by TAFU were appreciated by district officials and HIV implementing partners for their role in health education, tracing and follow-up of women and children lost to follow-up and referring women and children in their villages to health facilities for HIV testing and care.

Indeed, most health workers and district officials described TAFU as one of the major community based programs with particular focus women and children living with HIV.

TAFU focuses on finding children living with HIV and retaining them in HIV care. During the process vulnerable households would be identified and linked to other partners for support (District official Ntungamo)

Most of the interventions by HIV implementing partners are general to all people living with HIV and

are health facilty based such as ensuring availability of laboratories and ARVs. TAFU is unique in that it focuses on HIV prevention and treatment in children at community level (District Official Mubende).

TAFU program complements other HIV interventions in target districts. TAFU program trained community support structures for children and families. Using VHTs and community resource persons, children living with HIV are identified, linked to health facilities for care and monitored to remain in care (District Official Soroti).

Emerging from the above narratives is that while most activities of stakeholders implementing HIV interventions are focusing on health facilities and target people living with HIV in general, TAFU interventions focus on children and at the community level. Thus TAFU interventions complimented those of other HIV implementing partners in target districts. In all intervention areas VHTs and CoRPs trained by TAFU helped to follow-up women and children who missed clinic appointments. The VSLA groups initiated under TAFU enabled caretakers of children living with HIV to address economic barriers to seeking and remaining in care.

### **Emerging Issues**

- TAFU was seen by study participants as a unique program that focuses on finding children living with HIV and retaining them in HIV care
- Focusing on paediatric HIV prevention and care at community level, TAFU interventions complimented those of other HIV implementing partners in target districts.

### 3.8 Challenges encountered during program implementation

Evaluation findings revealed that TAFU program interventions such as training VHTs and CoRPs, community dialogue and advocacy meetings, district coordination meetings, peer support meetings, home visits and VSLAs have contributed significantly in addressing the challenges affecting paediatric HIV prevention and care at family, community and health facility levels. However, several challenges were still prevalent as shown in figure 5 and as discussed in the following sub-sections.

Figure 5: Major challenges affecting paediatric HIV prevention and care in TAFU districts



### 3.8.1 Individual child and caregiver challenges

At individual caregiver and child level, major challenges across all TAFU intervention districts that continue to limit use of paediatric HIV prevention and care services are: shortage of food, poverty, stigma and lack of disclosure. In some cases some children on ARVs had not been disclosed to and thus did not understand the need to adhere to treatment while in other instances HIV status for children and women on the eMTCT program were kept a secret including to those who would help in their care mainly due to fear of stigma. While sensitisation and counselling sessions had been done as part of the TAFU program and stigma was reported to be reducing its continued prevalence at home, in schools and community settings depicts the need for sustaining such efforts.

### 3.8.2 Family and community level challenges

At family and community level, the persistent barriers were: poverty a major constraint in attending the required clinic visits for viral load monitoring, drug refills and treatment of opportunistic infections. Poverty was also mentioned as a major challenge in meeting the nutrition needs of children and sustaining ART adherence. Indeed in all the study districts, children, caregivers and health care providers mentioned shortage of food as a hinderance to ART adherence.

Many children complain that they fail to take ARVs when they have nothing to eat (Health worker Kyenjojo).

# Sometimes we are told to take drugs (ARVs) but when we have not eaten which is difficult. (FGD-Children, Ntungamo)

Shortage of food was compounded by unfavourable seasonal changes which reduced crop yields and COVID-19, especially for those who were engaged in small businesses as a source of livelihood.

We had delayed rains and much sunshine which spoilt crops so many people do not have food which is a challenge for adherence to ARVS (FGD Women living with HIV Soroti).

Due to COVID-19, many people who had small businesses lost them during lock-downs. Thus many families including those of people living with HIV could lononger afford food yet its important for adherence (FGD Caregivers Mubende)

At family and community levels, children and women living with HIV face stigma inform of 'name calling' because of their HIV status. Some children living with HIV reported parents refusing them to play with their children, due to fear of transmitting HIV, a reflection of persistent knowledge gaps on HIV transmission.

Low Male involvement in paediatric HIV prevention and care. While male involvement in the PMTCT program and care for children living with HIV is advocated for and has improved over the years owing to community sensitization and advocacy under TAFU, it remains low and limits utilization of paediatric HIV prevention and care services.

Men are very important in the care for women and children living with HIV because of their power and control of resources. However, many men leave care for children to women and do not provide money needed to take children or for women to go to hospital (District Official Soroti District)

Some men fear to be identified with those children and have left all the care for children living with HIV to women. When a woman is not available at home

# children are not taken to hospital or given ARVs (FGD caregivers Kyenjojo District)

Implied in the above narratives is the fact that low male involvement continues to limit women and children from accessing HIV services and the required support for adherence to ARVs and clinic appointments.

### 3.8.3 Health facility level challenges

At the health facility level, continued stock out of critical supplies like HIV test kits, ARVs, drugs for opportunistic infections were major challenges. The VHTs, CoRPs and networks of PLHIV trained by TAFU closely monitored stock out of critical HIV supplies and provided prompt feedback to TAFU partners and district health teams to take action. In addition, NAFOPHANU conducted advocacy campaigns in which issues of stock out of ARVs and HIV test kits were highlighted and called on stakeholders to strengthen the supply chain.

Evaluation findings indicated that while supply of ARVs had improved greatly during the TAFU project period, stock-out of ARVs were still a challenge. Some health workers and district officials mentioned that the district and HIV implementing partners often re-distributed ARVs and HIV test kits from one facility to another. Due to stock out of ARVs, health workers resorted to shorter drug refills (1-2 weeks) as opposed to 3-monthly drug refills. The implication here is that women and caregivers of children had to bear with more health facility visits to collect drugs and which increased care expenses.

COVID-19and related restrictions on movement was another challenge. Most study participants mentioned that Covid 19 and related lock downs resulted in high transport costs to drug refill centres and limited opportunities to earn income needed to meet health care requirements.

School activities to support children living with HIV were not implemented due to closure of schools because of COVID-19.

Limited number of health workers at health care facilities was another challenge. Having few health workers in the context characterized high patient load resulting in delays at health facilities during ART refills and health workers having inadequate time to identify and address the concerns of children, their caregivers and women living with HIV. There were also challenges in tracking and documentation of referrals from VHTs and CoRPs as these are not part of health facility information management reports.

At some health facilities, negative attitude of health workers was noted as a challenge for children and women living with HIV. Examples of negative attitude of health workers include: use of abusive language, shouting and not attending to women and children promptly.

There is a particular health worker here. When he is here, he shouts at us. He says "go back home and pick your medicine on another day (when you are late)" and sometimes he tells your mother to give you money to return to the facility another day. This

# especially happens when we forget our medicines at home .... (FGD Children, Mubende District).

### 3.8.4 Programme Level Challenges

Limited budget and geographical coverage of the program – most program stakeholders noted that TAFU program covered very few sub-counties in each of the target districts mainly due to limited resouces. Limited geographical coverage of the program limited program impact and lessons about the model.

Limited number of community resource persons trained. The VHTs and CoRPs trained and supported by the program did not cover all parishes and villages in the target areas. As such, some community resource persons were overstretched and some villages/parishes in target subcounties were unserved. This limited the effectiveness of the program.

While the strategy of using trained VHTs to mentor others helped to increase the number of community resource persons involved in paediatric HIV prevention and care, these were not provided with reference materials and other items such as gum boots, bicycles and bags for use in their work which limited their effectiveness. As such, using a blended approach to capacity building involving use of trained VHTs to mentor other CoRPs in target communities supplemented by targeted training and provision of reference materials can help to increase the needed pool of CoRPs.

Documenting and tracking the activities of VHTs and CoRPs was another challenge. Most activities done by VHTs and community resource persons such as counselling, health education during home visits and some referrals to health facilities were not documented nor reflected in health facility and project reports. While TAFU program provided food to some vulnerable households during the COVID-19 outbreak, food was not adequate to reach all vulnerable households. Besides, lack of comprehensive interventions as part of the TAFU program to address food insecurity and nutrition remained major barrier to ART adherence and attaining viral load suppression in the target group.

Mobile populations across all TAFU target districts where some people already sensitized or in care relocated to other areas outside the TAFU target districts. This negatively affected continuity in care for women and children but also negatively affected the gains from community health education activities. As such, VHTs and health workers instead of building on previous health education sessions they often had to start afresh when faced with new community members.

Lack of resources to ensure continuity of community activities was another challenge. Whereas health facility, sub-county and district leaders pledged to continue supporting community activities by VHTs and other community resource persons, there was lack of clear plans and budgets to facilitate VHTs, CoRPS and HWs to sustain community activities beyond TAFU. Most stakeholders expressed fear that community activities are likely to slow down due to limited resources.

High community expectations such as the expectation for support with food, school fees, clothing, drugs not available at health units and transport refund for attending the clinic and community health education activities.

- Limited program budget and coverage of sub-counties, health facilities and schools.
- Limited number of VHTs and CoRPs trained.
- Challenges in tracking referrals and other activities of VHTs at health facility levels.
- Migration of community members disrupted gains from community health education activities.
- Continued stock out of critical HIV supplies like HIV test kits & ARVs Limited resources for community activities
  - High community expectations from the program

#### 3.9 Lessons Learnt

#### 3.9.1 Building linkages between communities and health facilities

Building linkages between community resource persons and health facilities improves identification, linkage and retention of children and women living with HIV in care. When VHTs and CoRPs are trained, mentored and linked with health facilities through regular joint progress review meetings, sharing of information, development and implementation of action plans, VHTs are a crucial linking pin between communities and health facilities.

Working with trained and experienced VHTs to mentor others is a promising strategy to increase a pool of CoRPs. Mentored VHTs require additional support in form of reference materials in the local language and items such as gum boots, bicycles, registers and field bags for use in their work.

Community resource persons and village health team members who doubled as experts are in general a preferred source of supporting children and women living with HIV. These draw on personal experiences living with HIV and taking ARVs to support others especially those newly diagnosed with HIV or with adherence challenges. VHTs who doubled as expert clients were also considered by caregivers of children living with HIV as unlikely to promote stigma compared to those not living with HIV.

Continuous training and mentorship of community resources persons to improve their knowledge and skills including on communication, guaranteeing confidentiality and updating them on new developments in the area of HIV are important. It is important for actors involved in community system strengthening programs like TAFU to provide reference materials in the language of CoRPs and VHTs as well as addressing their logistical needs such as gum boots, bags, bicycles to enable them work effectively.

Children and women living with HIV continue to face stigma at home, community and health facilities. Thus, activities that support children and women to build resilience against stigma as well as those geared at stigma reduction at home, in the community and health facilities should be sustained.

Community outreach services conducted jointly by health care workers and VHTs bridges community-facility service gaps and reach vulnerable and excluded community members.

Health facility challenges such as stock out of critical supplies, having a limited number of health workers at health facilities, lack of funds for community activities and sustainable mechanisms to track the contribution of CoRPs limit the success of paediatric HIV prevention and care interventions. These require broader and sustained health system improvement interventions

along all the six building blocks of the health system recommended by the World Health Organisation which are: service delivery, health workforce, health information system, financing and leadership (16).

Shortage of food remains a major barrier for women and children to adhere to HIV treatment and subsequently to viral load suppression. The COVID-19 pandemic and related lockdowns compounded food shortages. Food relief provided as part of COVID-19 response projects by TAFU partners were highly appreciated and contributed to retention in care and identification of children and adults living with HIV who had been lost to follow-up.

### 3.9.2 Lessons from Village Savings and loan associations

Village Savings and loan associations provided a good avenue for TAFU partners to address the economic and psychosocial challenges faced by children living with HIV and their caregivers. These groups facilitated access to credit to start or improve income generation activities, experience sharing among caregivers and health education talks on paediatric HIV prevention and care integrated in VSLA group meetings.

Integration of VHTs and CoRPs in VSLA groups enhanced opportunities for continued learning and awareness raising about eMTCT and paediatric HIV care.

The VSLAs for VHTs and other community resource persons were a source of motivation for community structures and hold potential for continuity of community-facility activities. These VSLAs provide opportunities for CoRPs to continue meeting, share experiences and continue learning from each other as well as enabling them to addressing their individual and family economic needs.

Linkage and involvement of sub-county and district officials including community development officers, district production and commercial officers in training, mentoring and monitoring VSLA groups provides opportunities for such groups to access additional financial and technical support from government programmes.

Village Savings and Loan Associations provided an opportunity and safe space for members living with HIV especially those newly diagnosed with HIV to share experiences including on fighting HIV related stigma as well as overcoming side effects of ART through ART literacy education talks and experience sharing including tips on addressing ART related side effects.

### 3.9.3 Working with Local Government Structures

Joint project coordination and review meetings involving district health teams and officials from other departments such as community development, agriculture and education provided an important space for stakeholders to appraise TAFU interventions, promote program ownership and increase resources for community interventions with potential to increase chances for sustainability.

Working with local government structures requires allocating resources to aid their participation in programme implementation, monitoring and evaluation.

While the local government structures and the Ministry of Health appreciates the role of VHTs and CoRPs in bridging the gap between communities and health facilities, inadequacy of resources for community system strengthening remains a key challenge.

### 4 Conclusions and recommendations

### 4.1 Conclusions

Evaluation findings indicate that the TAFU program contributed to strengthened community systems for identification, tracing, referral, follow-up and support of women and children living with HIV. The TAFU program improved uptake and retention of women and children in HIV prevention and care services. Through the TAFU project VHTs and CoRP received trainings to support children and women living with HIV. The evaluation showed that VHTs and CoRPs played a crucial role, but that the training they received could be improved.

The TAFU program initiated and supported 48 village savings and loan associations (VSLA) for women and caregivers of children living with HIV in the target communities. Overall, 1,442 women living with HIV and caregivers of children living with HIV have been supported through VSLAs. The VSLAs under TAFU are a sources of economic empowerment, psychosocial support, knowledge and skills and motivation to initiate and remain in care.

The TAFU program initiated and supported 21 VSLAs for VHTs and CoRPs. These have enabled VHTs and CoRPs to mobilise savings, meet regularly and borrow to start income generating projects to meet personal and family needs. As such these VSLAs were a source of motivation for VHTs and CoRPs and provide opportunities for likely continuity of community activities.

The TAFU program increased community awareness about paediatric HIV prevention and care and contributed to reducing HIV related stigma. Movement of some people from TAFU program areas limited the gains in community awareness about paediatric HIV. The program also increased the visibility of paediatric HIV and needs of children living with HIV at community and district levels.

The COVID-19 and related lockdowns exacerbated challenges faced by women and children living with HIV and their caregivers. Challenges of access to health facilities, cost of transport to health facilities, shortage of food, poverty, stigma and violence increased during the COVID-19 outbreak and negatively affected ART adherence. As a response the TAFU program provided food to the most vulnerable families, supported health education and counselling for adherence and health workers and VHTs to distribute ARVs to community members who could not access health facilities. Through the COVID-19 response which included nutritional support, viral load suppression increased among children living with HIV. This exposes and emphasized the urgent need for a sustainable approach to nutritional support for children living with HIV and their families.

Overall, the TAFU program was seen by stakeholders as relevant and with focus a unique focus on strengthening linkages between health care facilities and communities for identification, follow-up, tracing and referral of women and children living with HIV between health facilities and communities in target areas. TAFU program enhanced the capacity of VHTs and CoRPs and linked them to health facilities for support and collaboration. Taken together, TAFU program interventions complemented paediatric HIV services by the Ministry of Health and partners in Uganda and contributed to increased enrolment and retention in HIV care for women and children in target districts. The community structures supported by TAFU program, particularly VHTs and CoRPs as well as the VSLAs are likely to continue providing services to children living with HIV and their caregivers beyond the program period. While the TAFU program, contributed to a reduction in non-disclosure of HIV status and stigma these are still prevalent in intervention areas and require sustained interventions. Evaluation findings also revealed a need to integrate food security

and nutrition activities in community health system strengthening interventions like TAFU, improving systems for supporting VHTs and CoRPs including provision of reference materials and other tools for use in the field and improving documentation and tracking of the contribution of VHTs and CoRPs while scaling up the TAFU model. A major concern of all stakeholders in the evaluation, was a need to implement the TAFU model on wider scale in current in current implementation districts and extending it to others to increase impact.

### 4.2 Recommendations

Aidsfonds and partners should mobilise resources to scale-up the TAFU model in current and additional districts for wider impact and learning. In intervention districts, the program interventions should cover all sub-counties and use community structures initiated in the past phases of TAFU such as VHTs, CoRPs, VSLAs, health workers, school and district authorities to build capacity in additional sub-counties and districts.

At the global level, Aidsfonds should advocate for other donors to invest in community strengthening approaches like TAFU.

TAFU partners should engage more with the Ministry of Health, other national level and international actors in paediatric HIV prevention and care to increase awareness about the model and advocate for more resource allocation for the implementation of community system strengthening interventions for paediatric HIV prevention and care.

Continue to strengthen linkages of TAFU with multi-sectoral teams at district and national levels beyond health to include community development, education, agriculture and production departments especially regarding the activities of VHTs, CoRPs VSLAs and schools so as to effectively meet the needs of children living with HIV and those of caregivers.

It is important for all actors in paediatric HIV care to increase support to families of children affected by HIV to enhance food security and nutrition. This can involve training family members in basic agronomic practices and enabling them to access seeds to start backyard/kitchen gardens to grow vegetables and fast maturing fruits for home consumption and surplus for sale. In times of crisis as was the case during the COVID-19 outbreak and related lockdowns, vulnerable families should be identified and provided with food relief and home based drug refills to sustain adherence.

More involvement of district officials in planning, implementation and review of program activities for sustainability. These include members of the District Health Team and officials from departments of community development, education and agriculture who should be involved in training and supervision of health workers, community resource persons, activities of VSLA groups. During TAFU program district officials were instrumental in training of community resource persons and VSLAs and were a source of additional resources to these groups.

Actors working with VHTs and community resource persons should support them to form VSLAs and train them on income generation activities as strategies to support them meet their financial needs and those of their families. In all districts some health workers had joined VHT/CoRPs VSLAs thus providing an added benefit of continued interaction between VHTs and health workers. Government and implementing partners involved in the support of VHTs and community resource persons should provide them with reference materials and other items such as gum boots, bicycles and bags for use in their work to improve their effectiveness. It is important for

TAFU partners to monitor whether VSLAs for VHTs will contribute to meeting some of these operational needs.

It is important for program implementers to conduct refresher training activities to further strengthen the capacity of VHTs and CoRPs. Refresher training sessions should cover HIV treatment, the need for treatment adherence and tips to support children and women living with HIV to adhere to ART and addressing challenges of HIV stigma and none disclosure of HIV status to significant others. In addition, VHTs and CoRPs should be provided with reference materials in the local language.

A blended approach to capacity building of VHTs and CoRPs involving use of trained VHTs to mentor other CoRPs in target communities supplemented by targeted training and provision of reference materials is recommended to increase the needed pool of CoRPs in target communities.

District and national level actors should continue to engage and build the capacity of District Networks of people living with HIV in community mobilisation, education about paediatric HIV care to improve treatment literacy and advocacy. These networks play a critical role in monitoring and advocating for improved HIV care services.

Actors in health promotion programs should continuously find points to integrate paediatric and adolescent HIV prevention and care with others programs aimed at promoting child, adolescent and maternal health to maximize benefits to target communities including identification and referral of children and adolescents living with HIV to care. Examples of ongoing interventions include; teenage pregnancy, cervical cancer screening, family planning, male circumcision and the women empowerment programs.

Stakeholders involved in community system strengthening should work collaboratively with the Ministry of Health to harmonise indicators and monitoring systems to track and report on the contribution of community resource persons on eMTCT, paediatric and adolescent HIV care.

### 4.2.1 District and MOH level recommendation

Health facilities should further be strengthened with recruitment of additional health care providers and ensuring adequate supply of critical supplies for HIV service provision including ARVs and HIV test kits.

District health team members should continuously monitor and address stigma at health facilities.

### 4.2.2 Aidsfonds and partner recommendations

Aidsfonds should increase advocacy for the TAFU model especially among stakeholders in paediatric and adolescent HIV prevention and care at national and international levels to increase buy-in and funding for community engagement interventions.

Disseminate lessons learnt from TAFU model implementation at district, national and international levels to increase awareness about the model and chances for the adoption of the model. This should include presentation at conferences and publication in peer reviewed journals.

### References

- 1. 't Hart D, Musinguzi M, Ochen R, Katushabe J, Rujumba J. Closing the gap in HIV prevention and care for children: early insights from a model that links communities and health care facilities in Uganda. Vulnerable children and youth studies. 2016;11(3):281-5.
- 2. Rujumba J. The Social Context of Prevention of Mother to Child Transmission of HIV (PMTCT) in Uganda: Mothers' and health care providers' experiences and lessons for programme improvement. 2012.
- 3. UNAIDS. Treatment 2015 Geneva: 2015.
- 4. WHO. Guide lines on the use of CD4, viral load and EID tests for initiation and monitoring of ART. Geneva: 2014.
- 5. The Republic of Uganda. Consolidated guidelines for prevention and treatment of HIV in Uganda Kampala: Ministry of Health, 2016.
- 6. Uganda AIDS Commission. National HIV and AIDS Strategic Plan 2015/2016- 2019/2020. 2015.
- 7. The Republic of Uganda. HIV and AIDS Uganda Country Progress Report 2014. Kampala: Uganda AIDS Commission, 2015.
- 8. UNAIDS. Global AIDS update Geneva: 2016.
- 9. Orikiiriza J, Nakawesi J, Kikaire B, Turitwenka D, Schlech W, Kambugu A, et al. Unmet needs persist in pediatric HIV programs: lessons from selected case studies in Uganda. AIDS. 2017;31(8):1196-9.
- 10. The Republic of Uganda. The HIV and AIDS Uganda Country Progress Report Kampala: Ministry of Health, 2014.
- 11. Rujumba J, Tushabe A. Towards an AIDS Free Generation in Uganda (TAFU) Program: A baseline survey conducted in Serere, Moroto, Napak, Mubende and Mityana Districts. Kampala: Stop AIDS Now!, iCCO Cooperation and Partners in Uganda. Kampala: 2015.
- 12. De Groot A, Tounkara K, Rochas M, Beseme S, Yekta S, Fanta Siby Diallo J, et al. Knowledge, attitudes, practices and willingness to vaccinate in preparation for the introduction of the HPV vaccine in Bamako, mali PLoS ONE. 2017;12(2):e0171631.
- 13. Elder JP, Lytle L, Sallis JF, Young DR, Steckler A, Simons-Morton D, et al. A description of the social–ecological framework used in the trial of activity for adolescent girls (TAAG). Health education research. 2007;22(2):155-65.
- 14. Sallis JF, Owen N, Fisher E. Ecological models of health behavior. Health behavior: Theory, research, and practice. 2015;5(43-64).
- 15. Stokols D. Translating social ecological theory into guidelines for community health promotion. American journal of health promotion. 1996;10(4):282-98.
- 16. World Health Organization. Monitoring the building blocks of health systems: a handbook of indicators and their measurement strategies. World Health Organization, 2010.