Towards an AIDS Free Generation in Uganda (TAFU) Program: Endline Survey Conducted in Serere, Moroto,Napak, Mubende and Mityana Distrcts

Final Report

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Dr. Joseph Rujumba
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ABBREVIATIONS

AAH	Action Africa Help
CHAU	Community Health Alliance Uganda
CUAMM	Doctors with Africa
DCU-TAIP	Deliverance Church Uganda – The AIDS Intervention Programme
eMTCT	Elimination of Mother-to-Child Transmission of HIV
FGD	Focus Group Discussion
HBC	Home Based Care-program of the Catholic Church in Moroto
HC	Health Centre
HIV	Human Immune-deficiency virus
HIV	Human Immunodeficiency Virus
HNU	Health Need Uganda
ICASA	International Conference on AIDS and STIs in Africa
IRC	International Rescue Committee
KII	Key Informant Interview
MoH	Ministry of Health
NAFOPHANU	National Forum of People Living with HIV/AIDS Networks in Uganda
NGO	Non -Governmental Organisation
NSP	National Strategic Plan
OVC	Orphans and Vulnerable Children
PAG-KIDEP	Pentecostal Assemblies of God – Karamoja Integrated Development Programme
PATA	Paediatric Adolescent Treatment for Africa
PLHIV	People Living With HIV
PMTCT	Prevention of mother-to-child transmission of HIV
TAFU	Towards an AIDS Free Generation in Uganda
UAC	Uganda AIDS Commission
VHG	Village Health Group
VHT	Village Health Team

EXECUTIVE SUMMARY

Introduction

This report presents results of the endline survey for the – Towards an AIDS Free Generation in Uganda (TAFU) program implemented in the in the 5 Districts of Serere in Teso Region; Moroto and Napak in Karamoja Region; and Mubende and Mityana in Central Region. The survey was commissioned by Aidsfonds and partners in Uganda and was conducted in July and September 2017. The endline survey was conducted to capture the perspectives of stakeholders regarding project contribution in relation to paediatric HIV prevention and treatment services in the target areas.

Methodology

This was a cross-sectional participatory assessment conducted in all the five TAFU project areas. Data for the study were collected through 53 focus group discussions conducted with mothers in PMTCT/eMTCT programme, partners of women attending PMTCT, children living with HIV, caregivers of children living with HIV, networks of people living with HIV, Village Health Team members (VHTs), religious and local leaders, teachers and members of Village Savings and Loan Associations (VSLAs). In addition, 16 in-depth interviews were conducted with children and women living with HIV and their care givers and 58 Key Informant Interviews (KIIs) with district officials involved in PMTCT and Paediatric HIV Care, health workers, staff of partner agencies, community and religious leaders and staff of other programmes on PMTCT/Paediatric HIV. Content thematic approach was used for data analysis.

Key achievements

As part of the TAFU program, VHTs, expert clients, peer mothers and other community resource persons conducted household visits to families with children and women suspected or known to be living with HIV in their areas and these were used to educate family members on HCT, eMTCT, care for children living with HIV and disclosure of HIV status. Those suspected to be living with HIV were referred to health care centres for further care.

The TAFU program promoted community and couple dialogue in homes where children and women are cared for in the five target districts. Dialogue meetings were an avenue to discuss issues generated during health facility information sessions and other concerns affecting community use of eMTCT and paediatric HIV services. Couple dialogue meetings addressed issues such as communication especially among discordant couples, HIV status disclosure, PMTCT, nutrition, ANC, drug adherence and the importance of pediatric HIV care/treatment.

TAFU program partners facilitated the formation of VSLAs to strengthen the economic capacity of families of children and women affected and living with HIV. Overall a total of 43 VSLA groups with a total of 1,008 members were formed and supported. Groups received training in financial literacy, income generating activities, saving, loaning, record keeping and group management. In most places groups were given top-up funding of 250,000 - 500,000/ Uganda shillings to

boost group funds available for lending to members. In addition to this training, groups in Moroto underwent a 20 hour additional training on 'Think Livelihoods' spread over 10 days.

The TAFU program supported peer support meetings for children and their caregivers at health facilities with sufficient numbers of children in the target districts. In collaboration with health care workers, VHTs and expert clients identified children and their caregivers and mobilised them to attend quarterly meetings held at health care facilities. In all the project areas, partners conducted community dialogue meetings in which community members, leaders, health workers, VHTs and expert clients jointly discussed issues affecting care for children and women living with HIV at family, community and health facility levels and generated/implemented actions to address the identified issues.

TAFU program prioritised capacity building for community resource persons and health workers to strengthen the link between community and health care systems to identify and care for women and children living with HIV. As part of the VHT capacity building, a VHT training manual and flip chart on paediatric HIV were centrally developed and used to conduct training of all community resource persons in the five target districts. The VHT flip chart was distributed to VHTs and health workers to serve as a reference guide during household visits and community dialogues. 327 VHTs were trained on eMTCT, paediatric HIV testing, treatment and care, referral mechanisms, follow up and home visits. The VHTs and other community resource persons increased the number of children in HIV care from 459 at baseline to 1,017 at end line survey.

TAFU program partners continuously shared lessons learnt from the program and lobbied stakeholders at health facility, community, district, national and international levels to adopt the TAFU model or address the challenges in paediatric HIV prevention and care. Quarterly exchange learning meetings were used to share progress and for partners to learn from and support each other. This enhanced the quality of program implementation, monitoring and documentation of promising practices.

The TAFU Model was documented and shared with stakeholders within and outside Uganda mainly through presentations at national and international conferences and one article was published in scientific Journal. This has increased interest in the need to addressing linkages between community and health facility systems as a prerequisite to improve eMTCT and paediatric HIV services.

Key challenges

The key challenges during implementation of TAFU I included; low geographical coverage by the program, recruitment of few volunteers, limited reference materials which was not even in local languages, low literacy levels especially in Karamoja Region and Phase out of Baylor Uganda that was a major HIV implementing partner in Karamoja region and Serere District which paralyzed implementation. In addition, there were challenges related to poor nutrition due food scarcity in all districts especially in Karamoja region; and inadequate training of service providers such as VHTs and other community resource persons.

Lessons Learnt

Developing partnerships between community resource persons and health facilities is possible and facilitates identification of vulnerable children and women; referring and retaining them in care. The VHTs who are expert clients are preferred to non-expert clients to support meetings for children and caregivers provide them with a unique opportunity to share experiences, challenges and opportunities for peer support; active involvement of local government officials and support supervision is critical to promote program ownership and increase chances for success and sustainability. VSLAs provide avenues to address economic, health information support and other needs of families of children and women living with HIV. Shortage of food limits women and children's enrolment in HIV care and adherence to treatment. Children living with HIV face stigma at home, in community and at school thus activities that support children to build skills to counteract stigma such as peer support groups and individual counselling as well as creating awareness on the need to support children living with HIV should part of program interventions.

Conclusions

The TAFU program strengthened systems for tracing, referral and follow-up of women and children living with HIV through training, support supervision, mentoring of health workers and community resource persons. Thus, the program contributed towards strengthening the capacity of communities and health facilities in the five target districts regarding e-MTCT and paediatric HIV care. Program interventions were appreciated by community members, health workers and district officials. In the two districts of Karamoja region that were silent about HIV prevention, testing and care with high HIV stigma, TAFU program created a foundation for families and communities to talk about HIV prevention, testing and care especially for women and children. The program socially and economically empowered 1,008 families to support mothers and/or children living with HIV to enroll and remain in PMTCT and paediatric HIV care through VSLAs. Overall, there was increased utilization of eMTCT and paediatric HIV services especially in Mubende, Mityana and Serere Districts. Whereas the numbers of children in care in Karamoja did not increase substantially, the program built a foundation for paediatric HIV prevention and improving care through building community and health care systems and linking them. The TAFU program increased community awareness about paediatric HIV and contributed to reducing HIV related stigma.

Recommendations for TAFU I

TAFU partners in Napak and Moroto Districts which are not part of the second phase of TAFU program should develop and implement at least one-year phase-out plan to facilitate smooth phase-out of target communities and improve chances for program sustainability to enable partners to strengthen key structures such as VSLA groups, VHTs, Church groups and improve collaboration with relevant district departments for sustainability.

For partners in Eastern and Central Uganda, during implementation of TAFU II program, it is important that follow up plans are developed and implemented to ensure continuity of key

interventions initiated under TAFU I. Use community structures and health facilities that participated in TAFU I for exchange visits and learning by structures in TAFU II. Active linkage of TAFU with the DHT, Community development, education and agriculture departments should be strengthened. Exchange visits for such groups to other progressive community groups should be prioritised.

In TAFU II, Local government officials should be involved beyond sharing reports in joint planning and implementation of activities such as training of health workers, community resource persons, VSLA groups and conducting joint support supervision to aid in addressing emerging issues in a timely manner and to ensure ownership and sustainability of program interventions and benefits beyond the program time frame.

Conduct whole site training at health facilities to benefit all health workers involved in the delivery of paediatric HIV prevention and care services.

Train community resource persons within their areas and in partnership with relevant LG officials. Partners should support community resource persons to form area specific associations as a mechanism for addressing their needs during and after the program. Program implementers should engage and build the capacity of District Networks of PLHIV.

Address nutrition challenges in relation to HIV especially regarding children. Future programmes should consider addressing nutrition challenges at health facility levels for severely malnourished children during the critical phases of engaging with care. Such interventions should include advocacy for the provision of ready to use foods for severely malnourished children at all HIV care centres and supporting families to produce their own food.

District and MOH level recommendations

Strengthen health facilities with more staff and regular supply of drugs, HIV test Kits and sundries and ensure continuation of support supervision by the district health team. The TAFU program initiated community mobilisation, support and follow-up program in the five districts should be integrated in the ongoing discussions to restructure VHTs and other community health promotion programmes. Documentation of referrals and other activities done by VHTs should be strengthened.

1.0 INTRODUCTION

1.1 Overview

This report is submitted to Aidsfonds formally Stop AIDS Now! and partners in Uganda in relation to an end-line survey for a 30-month program – *Towards an AIDS Free Generation in Uganda (TAFU) implemented in the 5 Districts of Serere in Teso Region; Moroto and Napak in Karamoja Region; and Mubende and Mityana in Central Region*. The project sought to reduce the number of new HIV infections and to increase the number of HIV-positive children on treatment in the five target districts in Uganda. The endline was conducted using participatory applied research methodology to ensure capture of perspectives of stakeholders regarding project contribution in relation to paediatric HIV prevention and treatment services in the target areas. Data for the study was collected during July and September 2017.

1.2 Background to the TAFU Program

In 2015 at the start of TAFU program, 140,000 children 0-14 years were estimated to be living with HIV (Ministry of Health, 2015) of which only 42% were on treatment. In 2016, UNAIDS estimated that 96,000 children under the age of 14 years were living with HIV in Uganda; 62% were on Anti-retroviral treatment (UNAIDS 2016). Besides, ARV coverage for HIV exposed children born to women living with HIV remains low estimated at 25% and most paediatric HIV prevention and care services were largely health facility based thus unable to reach hard-to-reach children to enrol or link them to care. The TAFU program was conceived to mobilize communities and create awareness around paediatric HIV prevention and treatment, empower families of affected children and enhance child friendly services through support to especially the lower level health facilities as well as galvanize community referral and linkage systems.

The 30-month TAFU program aimed to increase the number of HIV-positive children on treatment and to reduce the number of new infections among infants in 5 districts of Napak, Moroto, Serere, Mityana and Mubende in Uganda. The program used a partnership approach involving; two Dutch technical organizations Aidsfonds (formerly STOP AIDS NOW!) and ICCO Cooperation and five Ugandan non government organizations: Deliverance Church Uganda – The AIDS Intervention Programme (DCU-TAIP) in Moroto**,** Pentecostal Assemblies of God – Karamoja Integrated Development Programme (PAG-KIDEP) in Napak, Health Need Uganda (HNU) in Serere, Community Health Alliance Uganda (CHAU) in Mubende and Mityana Districts; and The National Forum of People Living with HIV/AIDS Networks in Uganda (NAFOPHANU). The program partners also collaborated with the Ugandan Ministry of Health (AIDS Control Program) and the District Health Service departments in intervention districts to build bridges between communities, households and health facilities.

The TAFU program Goal

To reduce the number of new HIV infections among infants and increase the number of HIV-positive children on treatment in the target districts.

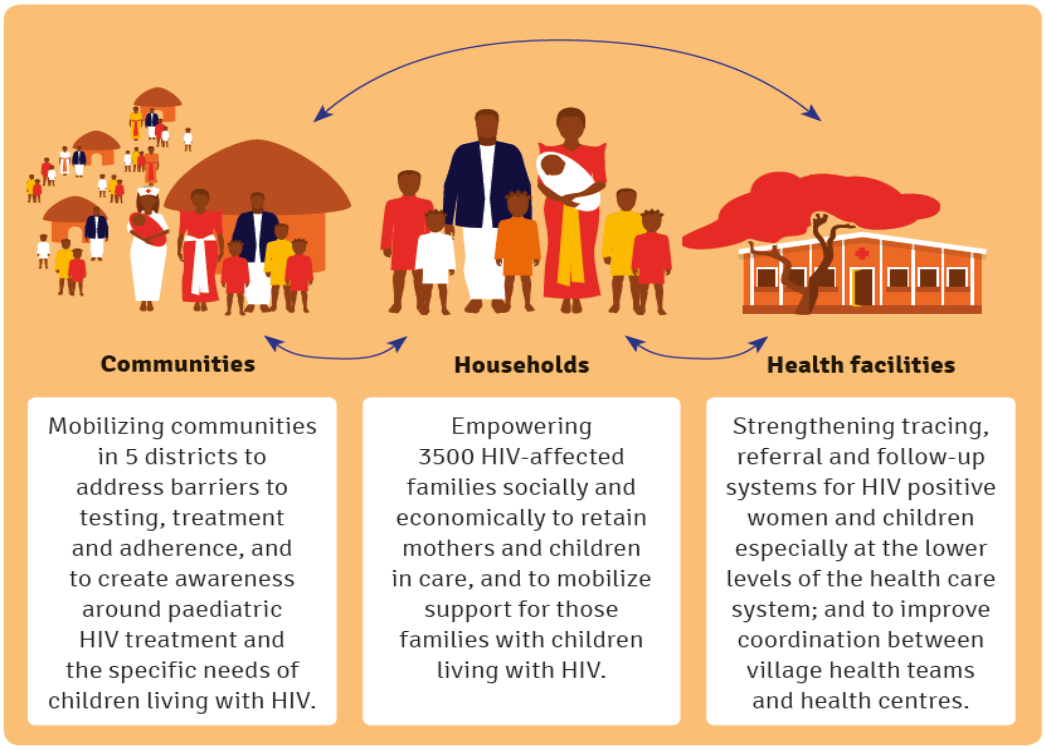
Specific aims

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

1.3 TAFU Program Outcomes and Model

The program outcomes are summarized in figure 1.

Figure 1: Expected outcomes of the TAFU Program

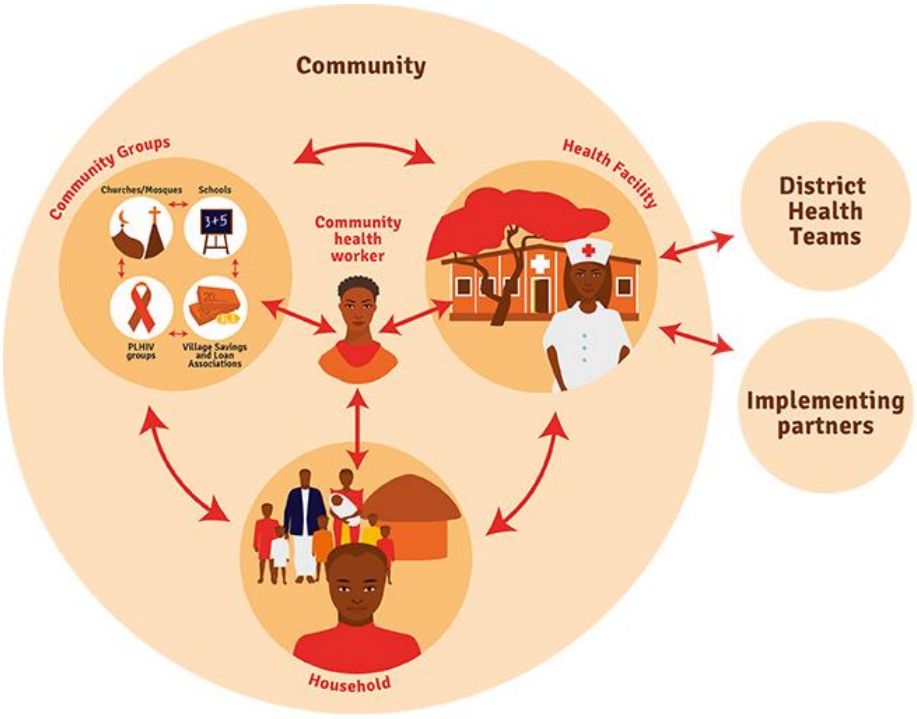


The TAFU Program Approach/Model

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 2). Community Systems which include community members, community resource persons (village health team members, persons living with HIV, teachers, community and religious leaders), community groups (women, religious, village savings and loan

associations and village health groups) and institutions such as schools, community based organizations and nongovernmental 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 2: The TAFU Program Model



As shown in the figure 2, the TAFU project sought to bridge that gap between communities and health facilities to prevent mother-to-child-transmission of HIV and to ensure HIV-positive mothers and children enroll and remain in care. Different actors were envisaged to collaborate in tracing, referral and follow-up of children affected by HIV.

1.4 Objectives of the endline survey

General objective

To assess the achievements, challenges and lessons learnt during the design and implementation of the TAFU Program.

Specific objectives of the end line survey

1. To assess the major achievements of the TAFU program as perceived by stakeholders (implementers and beneficiaries)?
2. To assess factors that influenced project effectiveness (facilitators and barriers) in relation to improving delivery and utilization of eMTCT and paediatric HIV care services)?
3. To document lessons learnt during the design and implementation of the TAFU project in the 5 target districts

2.0 METHODOLOGY

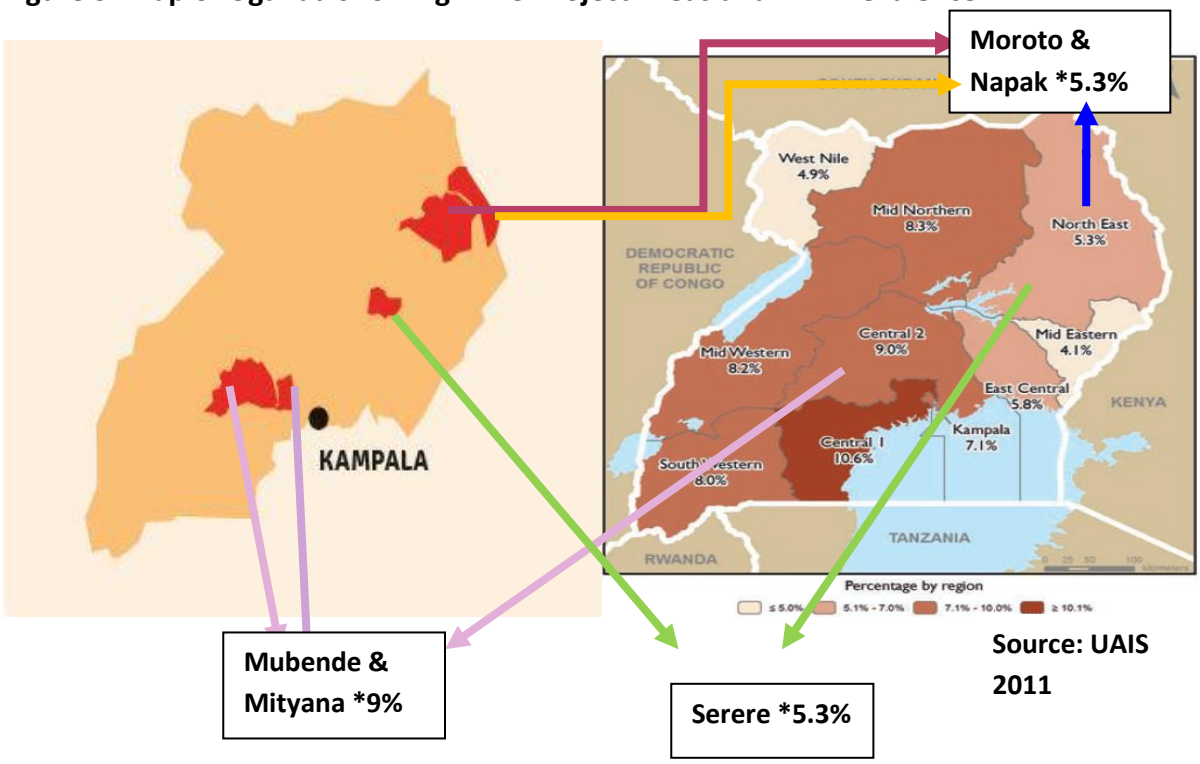
2.1 Introduction

This was an applied research involving active participation of project partners throughout the process of the study to ensure that results inform adjustment of project interventions to increase effectiveness. Applied research seeks to help policy makers, practitioners and participants to make decisions and act to improve human conditions or solve practical problems (Ulin P.R., Robinson E.T & Tolley E 2005). In this regard, the endline survey assessed the effectiveness, achievements, facilitators, challenges and lessons learnt from TAFU project. A mixed method design with both quantitative and qualitative methods of data collection was adopted for the study. This was premised on the complementary nature of the two designs.

2.2 Sampling

Given the need to compare changes among intervention districts, the study was conducted in all the five target districts of Serere in Teso Region; Moroto and Napak in Karamoja Region; and Mubende and Mityana in Central Region (Figure 4).The assessment was conducted in each of the project intervention sub-counties (total 12 sub-counties)and 22 target health centres (HCs) which were included in the baseline (table 1).In Mubende District, while the baseline was conducted at Kassanda HC IV in Kassanda Sub-county the health centre was replaced with Kiganda HC IV following guidance from the District Health Team. Thus during field work baseline data at Kiganda HC IV was obtained retrospectively. In Napak, Matanyi hospital was also added in the TAFU program, mid-way but it was not possible to obtain baseline data as the time frames would vary. However, qualitative data was collected from all the health centres.

Figure 3: Map of Uganda Showing TAFU Project Areas and HIV Prevalence



***Regional HIV prevalence among 15-49 both sexes -Uganda AIDS Indicator Survey 2011**

Preliminary results of the 2016 Uganda Population Based HIV Impact Assessment show that a decline in national HIV prevalence to 6%. HIV prevalence in central 2 region where Mubende and Mityana fall reduced from 9% to 7.4% and that for North East where Karamoja and Sere fall declaimed from 5.3% to 3.4%.

Table 1: Summary of Study areas by partner and district

Partner	District	Sub-county	Health Centre
PAG-KIDEP	Napak	Iriiri	Iriiri HC III
			Nabwal HC II**
		Lokopo	Apeitolim HC II
			Lokopo HC III
TAIP	Moroto	Rupa	Rupa HC II
			Kidepo HC III
		Southern Division	Nakapelimen HC II
HNU	Serere	Olio	Oburin HC III
			Akoboi HC II
			Serere HC IV
		Kateta	Moru HC II
			Kateta HC III
		Pingire	Pingire HC III
		Labor	Aarapo HC II
CHAU	Mubende	Kasyambya	Kasambya HCIII
			Kaboo HC II
		Kiganda	Kiganda HCIV
	Mityana	Bulera	Bulera HCIII
		Kikandwa	Kikandwa HCIII
		Kalangalo	Kyantungo HC IV
Grand Total	**5**	**13**	**20**

***** The HC was replaced with Matanyi Hospital midway in program implementation.***

2.3 Data Collection Methods

Overall, qualitative and consultative methods of data collection were used with varied project stakeholders at project level (partners), district (DHT, PMTCT, HIV focal persons, Community Development), Health Facility (Health workers involved in PMTCT and Paediatric HIV Care) and project beneficiaries. The main methods of qualitative data collection were Focus Group Discussions (FGDs), in-depth interviews and Key Informant Interviews (KIIs).

Focus group discussions (FGDs) were conducted with mothers in PMTCT/eMTCT programme, Partners of women attending PMTCT, Children living with HIV, caregivers of children living with HIV, Networks of people living with HIV, Village Health Team members (VHTs) and members of Village Savings and Loan Associations. Overall, a total of 53 FGDs of 6-8 participants each were conducted with various project stakeholders (Table 2). On average, each focus group discussion lasted 45 to 90 minutes and was conducted by two people, one as a facilitator and the other as a note taker. The FGDs were conducted by experienced research assistants and most were done in the local languages spoken in each of the study settings. A few of the focus group discussions especially those with some VHTs and Networks of people living with HIV were conducted in English.

To get a deeper understanding of the changes attributable to TAFU project, 16 in-depth interviews were conducted with children and women living with HIV and their care givers. In addition, 8-17 key informants per district (total 58KIIs) including with: district officials involved in PMTCT and Paediatric HIV Care, Health workers, staff of partner agencies, community and religious leaders and staff of other programmes on PMTCT/Paediatric HIV were conducted.

The focus of the qualitative data collection was to provide an in-depth understanding of stakeholders about the program and its contribution in improving access and utilisation of PMTCT and Paediatric HIV Care services in the target districts. This was meant to appraise the effectiveness of the program, challenges encountered, lessons learnt and suggestions to improve paediatric HIV prevention and care services.

The quantitative component of the study involved retrieval and analysis of data from target health facilities on the three impact indicators 1) number of children tested 2) number of children living with HIV on ART 3) number of children born free from HIV among those of HIV positive mothers. In addition, information on utilization of PMTCT services including: pregnant mothers attending ANC, counselled and tested for HIV, received HIV test results, number of women tested HIV positive, number of women who received ARVs for PMTCT and for their own care was collected. Data for this component of the study were obtained from the Ministry of Health Data base and health facility records/reports. A health facility check list was designed to capture key health system indicators in relation to PMTCT and Paediatric HIV care including: availability of PMTCT, Adult and Paediatric ART services, staff trained on PMTCT and Paediatric HIV care, paediatric and Early Infant Diagnosis of HIV testing, support groups for mothers/families in PMTCT and for children living with HIV, linkages with communities for mobilisation and education on PMTCT 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. TAFU program partner reports were also reviewed. The main outcome of this phase was to capture quantitatively the current status of PMTCT and Paediatric HIV services and compare it with the situation before program implementation.

The consultant reviewed key HIV policy and strategy documents at national level including; the Uganda AIDS Indicator Survey (UAIS 2012), The Uganda National HIV and AIDS Strategic Framework, The Uganda National HIV prevention strategy, the National HIV and AIDS M&E Plan, PMTCT prevention strategy and the Uganda Country HIV and AIDS response reports

among others. The main outcome of this phase has been to place end line study findings within the broader national context. Data were collected by the consultant, a research associate, together with project partner staff/research assistants. At the end of fieldwork in each of the study districts, a de-brief meeting was held with partner staff and research assistants to capture key insights and observations from the evaluation.

Table 2: Summary Data Collection Methods

Districts	KIIs	IDIs		FGD								
	District	Care givers	Children	PMTCT	VHTs	VSLA/ Care givers	PHAs	Children	Local/ religious leaders	Couples		Teachers
Moroto	District =1 TAIP=1 Health facility=7 Local/Religious leaders=1 PHAs/Peers=1 VHT F/P=1	1		3	3	2		2		Men 1	Women 1	
Napak	District =1 Sub-county=1 PAG-KIDEP=3 Health facility=5		3	3	2	3	2	1	2			
Serere	District =1 Sub-county=1 HNU=2 Health facility=6 PHAs/Peers=1	2	1		2	3		3				2
Mubende	District =3 Sub-county=1 CHAU=1 Health facility=3	1	1	2	2	**3**		2				
Mityana	District =3 CHAU=1 Health facility=4 Local /Religious leaders=5 PHAs/Peers=3 VHT F/P=1	3	4	2	2	3		2				
Total	**58**	**7**	**9**	**10**	**11**	**14**	**2**	**10**	**2**	**1**	**1**	**2**

2.4 Data Analysis

At the end of data collection in each of the study districts, a research team debrief meeting with program partner (s) was held to share emerging issues from the study. Qualitative data from focus group discussions and key informant interviews were analyzed manually using content thematic approach. This involved reading interview and discussion notes to identify themes and sub-themes which were used to group data for interpretation. Matrices and selected direct quotations from the discussions and interviews have been used in the presentation of endline findings. Quantitative data from health facility checklist was entered and analysed using Epidata (version 3.1) to generate frequencies. Endline findings were compared with those of the baseline study.

2.5 Ethical Considerations

This study was carried out as part of the TAFU activities in the target districts. Approval was obtained from the School of Medicine College of Health Sciences, Makerere University, Ugandan Ministry of Health and respective District Health Officials. The specific partners in each of the districts provided information about the endline study to key stakeholders and requested for their participation and mobilised study participants. Partners were also in charge of all 'door opening' for the study during fieldwork. All partners had ongoing interventions in the study districts and thus built on the existing good working relationship with district and community leaders. Informed consent was obtained from all study participants before conducting interviews and discussions. Ascent was obtained for children below 18 years and their caregivers consented before children and adolescents participated in the study. The research team informed study participants about the survey and requested for their voluntary participation. All respondents were assured of confidentiality concerning the matters discussed.

2.6 Study Limitations

Gaps in data at most health facilities and having multiple registers made access to some data difficult. For instance, at most health facilities data on women retested for HIV, exposed infants tested for HIV, children born free from HIV among those of HIV positive mothers, those lost to follow-up were not readily available. Also, some inconsistencies were noted in data at some health facilities especially regarding clients in HIV care.

The study was limited to HC IV, III and II thus does not include perspectives from hospitals (except Matanyi Hospital in Napak) a level where most paediatric HIV services are found. Hospitals were not targeted by the program. None the less perspectives of health workers, children and their caregivers at Matanyi Hospital in Napak District reflected similar concerns as those elicited from health facilities and caregivers elsewhere.

3.0 TAFU ENDLINE FINDINGS

3.1 Introduction

In this section, findings of the TAFU program evaluation are presented based on evaluation tasks laid out in the terms of reference.

A review of the project proposal, monitoring and evaluation framework and program reports revealed that the program set out to contribute to a reduction in new HIV infections among infants and increase the number of children living with HIV on treatment in the target districts. Specifically, the program intended to deliver the following outcomes:

1) Empower 3,500 HIV affected families socially and economically to retain mothers and children in care and to mobilize support for those families with children living with HIV.

2) Mobilize communities in the 5 target districts to address barriers to testing, treatment and adherence and to create awareness around paediatric HIV treatment and the specific needs of children living with HIV

3) Strengthen tracing, referral and follow-up systems for HIV positive children especially at the lower levels of the health care system; and improve coordination between village health teams and health centres.

4) Build evidence and interest to upscale the TAFU approach

Throughout the endline assessment, the evaluation team assessed the extent to which the program has delivered on these outcomes and the findings are presented in the following sections.

Table 3: Key TAFU achievements

Indicator	No Achieved
No of household visits done by community resource persons	3,839
No of people reached through community dialogue meetings	**9,808**
No of people reached with information on paediatric HIV through health facility information sessions	**7,338**
No of VHTs and other community resource persons trained	1378 (327 VHTs&1051other CoRPs)
No of Children tested for HIV	**5,051**
No of children in care in target areas at baseline 2015	**459**
No of children in care in target areas end line 2017	**1,017**
No of women enrolled in eMTCT/HIV care	**1,355**
Women and caregivers of children supported in VSLA groups	**1,008**
Number of peer children/adolescent peer support groups formed/supported	**16**
Number of children supported through peer support groups	**859**

Source: Project reports 2017

3.2 Empowering 3,500 HIV affected families socially and economically to retain mothers and children in care and to mobilize support for those families with children living with HIV.

The evaluation findings revealed that TAFU program partners implemented activities at community and health facility levels geared at improving knowledge and understanding of paediatric HIV care. The major activities undertaken to empower families of children and women living with HIV include: household visits, community dialogue meetings, health facility information sessions, identification and training of VHTs, formation and support of Village Savings and Loan Associations (VSLAs) through capacity building, boosting their savings by providing them with top up funds, linkage to other institutions and couple dialogue sessions.

3.2.1 Improving caretaker Knowledge on HIV testing, prevention, treatment and care for children and women

A review of project reports and interviews with project stakeholders revealed that as part of the TAFU program, VHTs, expert clients, peer mothers and other community resource persons conducted household visits to families with children and women suspected or known to be living with HIV in their areas. Household visits were used to educate family members on HIV counselling and testing, elimination of mother to child transmission, care for children living with HIV and disclosure of HIV status. Children and women suspected to be living with HIV were given referral advice and forms to health care centres where HIV counselling and testing services were provided. In such cases follow-up visits were made to assess compliance with referral and assess outcome. For children and women in HIV care, household visits were used to assess adherence to treatment and provide the necessary support. In some instances, household visits were used to follow-up children who missed clinic appointments. Evaluation findings revealed that TAFU program also supported health care workers especially in the Karamoja region to conduct home visits particularly to newly diagnosed women and children living with HIV.

Discussions with district officials, health workers at the target health facilities and community members revealed that the household visits by community resources persons and health workers as part of TAFU program helped to identify and refer women and children for HIV testing, link those found to be living with HIV to care and support those with challenges of adherence to treatment.

> *The VHTs under the programme would get lists of children lost to follow-up from health facilities in their area or children mentioned during community dialogue meetings who need help. Their homes would be visited, and support provided based on needs on ground. During such visits, some children lost to follow-up would be found and re-engaged with the health care system (VHT Coordinator Mubende).*

> *There is a child living with a grandmother who was very sick and malnourished. The grandmother was frustrated that the child would refuse food. When we visited their home together with the VHT we realised that the child had mouth sores...we advised the caretaker to take the child to the health centre for treatment. This happened, and the child got better. The grandmother was advised on how to feed the child as well...(Health Worker, Mityana District).*

> *During one of the outreaches there was a child living with HIV...who was being neglected by his father after the mother had divorced. The neglected boy was at the verge of death. But during one of the outreach visits he (the boy) was identified and Health Need Uganda helped in treating him at Serere HC IV. The father had stopped picking for him ARVs and forced him to drop out of school,*

wanting him to die. The boy is now very fine and taking his medication (KI-Kateta moru, Serere).

What is emerging from the above narratives is that home visits by health workers and community resource persons supported by TAFU enhanced care, follow-up and support for children living with HIV in the target areas.

The main challenge of household visits was the limited number of community resource persons, continued stigma and lack of resources to address the practical challenges and needs of families. Indeed, some health workers and project staff mentioned that often they spent personal resources when they visited households of vulnerable children.

Communities expect practical help. You can visit a family and find the child is sick or they have nothing to eat. You end up giving some help where you can, but most times we also do not have what to give (FGD VHT, Mityana).

After referring and encouraging mothers to adhere to drugs, infected mothers on re-turn come back to VHTs asking for support in terms of food since they find it difficult to take drugs without food (VHTs-Kidepu H/C Moroto).

Mothers living with HIV/AIDs are always expecting money after being talked to by VHTs…VHTs are not trained on how ARVs are swallowed which makes tracing and prescribing very difficult (VHTs-Kidepu H/C Moroto).

The implication here is that future programmes with home visits targeting vulnerable populations should foster linkages with other actors or allocate resources for provision of practical help to vulnerable populations. Indeed, project partners observed that for most children who are lost to follow-up, when found their immediate needs such as food and transport to health care facilities required material or financial support.

Emerging issues/Lessons

- Household visits by health workers and community resource persons helped to identify and refer women and children for HIV testing, link those found to be living with HIV to care and were an avenue to provide adherence support.
- Health worker visits were preferred by mothers and children who had recently tested and found to be living with HIV to visits by community resource persons.
- Families of children living with HIV especially those lost to follow-up require immediate material and financial support to re-engage children and sustain them in HIV care. This requires resource allocation to meet such practical needs when they arise and building linkages with other actors to address needs beyond the program.

3.2.2 Support VHTs and health workers to conduct facility based information sessions

The evaluation revealed that TAFU program supported VHTs, expert clients, health care workers and program staff to conduct health facility based information sessions. These sessions' targeted people seeking care in outpatient clinics, antenatal care and young child clinics and their caregivers. The sessions provided information on HIV testing, paediatric HIV, eMTCT, drug adherence, nutrition, ANC, family planning and male involvement. The number of sessions and people reached are summarised in table 3.

Table 4: Number of Health facility information sessions and people reached by partner

Partner	Number of Sessions	People reached with Health facility sessions
CHAU	62	2,381
HNU	32	1,858
TAIP	24	1,434
PAG	28	1,665
Total	**146**	**7,338**

Data Source: Program partner reports 2017

Interviews with community resource persons and health workers revealed that health facility sessions helped to increase understanding of paediatric HIV prevention and care as well as identifying and solving the challenges faced by mothers and children in HIV care. Some of the concerns raised by women and children during health facility sessions included; stigma and discrimination and challenges with adherence. Health facility sessions also provided space for community members to seek clarification from health workers on issues they had not understood in relation to HIV and care for pregnant women and children living with HIV. On the value of these sessions some key informants noted;

> *Health facility sessions were important in providing information to women, children and their caregivers. Women and their children share experiences and encourage each other. The sessions also helped people who have not tested for HIV to test... (HW Mityana District).*

> *Facility based sessions helped to erase local norms for example "women believe ...if you wash your private parts every time you have sex with an infected person, you won't get HIV" (KI -Kateta Moru Serere District).*

> *During health facility sessions, some women and children living with HIV, who had dropped out of care were mentioned. So we (VTH) got their details, visited their homes and re-engaged them in care…(FGD VHT, Mubende).*

Emerging from the above narratives is that health facility information sessions were key in increasing knowledge on HIV, care for children living with HIV and re-enforced community follow-up and support interventions for women and children in HIV care.

Women and children also praised the health facility sessions for giving them the space to share experiences, discuss the challenges they encountered in seeking HIV services and receive guidance on how to address the challenges. In this regard, facility sessions enhanced care for women and children living with HIV.

Emerging Issues/Lessons

- Health facility sessions provided an avenue for health workers, community resource persons and the community members to interact and devise solutions to address challenges faced by women and children living with HIV.
- Some issues identified in health facility sessions such as stigma, loss to follow-up, neglect of children living with HIV guided planning and conduct of targeted household visits and community dialogue sessions to generate solutions.

3.2.3 Identify and refer Children and women for HIV testing and care

Identification and referral of women and children to health facilities for HIV testing and HIV care was a major activity under the TAFU program. Endline findings revealed that all community activities including household visits, community dialogue meetings, community sensitisation meetings were aimed at raising awareness on the need for HIV testing and enrolling in care if found to be living with HIV. Re-engaging women and children who had droped out of care was another area of focus. Overall, 3,839 house hold vists were conducted by community resource persons . A review of health facility reports indicated that overall, the number of children in care in all TAFU program intervention districtsincreased when comparing the baseline and endline results (table 4 and figure 4).While at baseline children at some health facilities were not yet on ART, endline findings indicated that all children in care were on ART. This finding is reassuring that the policy of test and treat for children living with HIV has taken root in the target areas. TAFU program through training of health workers on paedatric HIV contibuted to the implimentation of the ongoing policy of test and treat in Uganda. Orientation of health workers and community resource persons under TAFU on the test and treat policy for all children and women in the eMTCT programme was a key contributor in this policy realisation in Uganda.

Table 5: Number of children on ART in target Districts at baseline and endline surveys

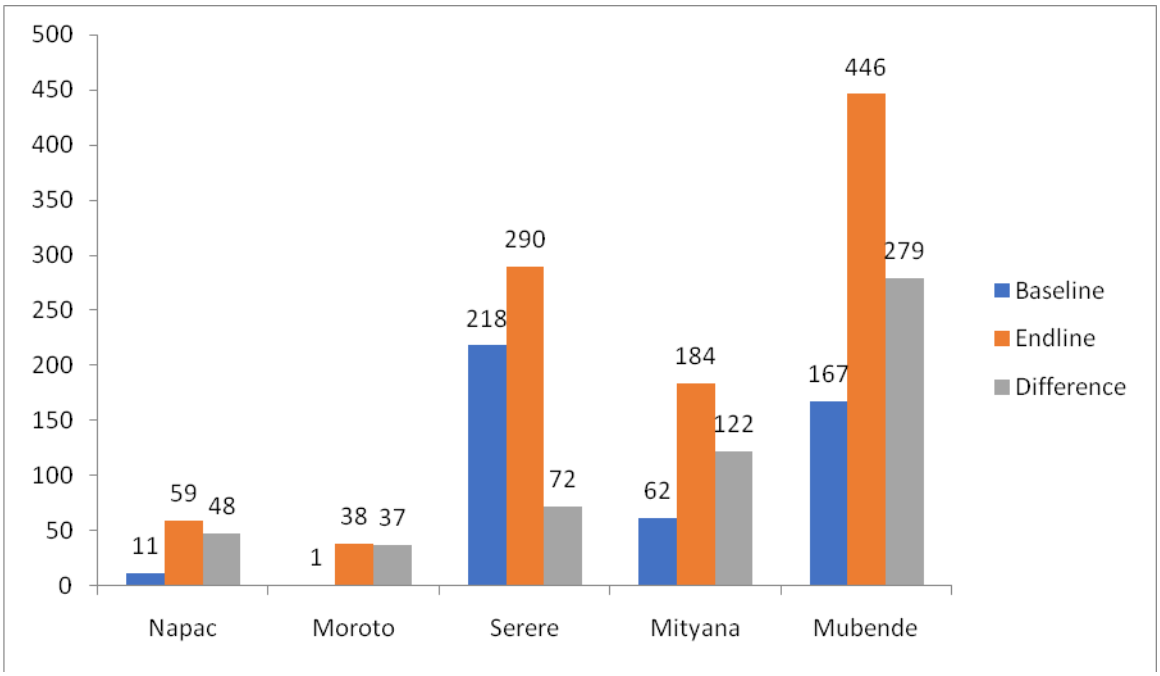
Number of children under 15 years in care					
District	**Baseline ***	**Endline at Partner HFs***	**Endline Other HFs****	**Total Endline [1]**	**Difference Endline-Baseline**
Napac	11	22	37	59	48
Moroto	01	3	35	38	37
Serere	218	256	34	290	72
Mityana	62	130	54	184	122
Mubende	167	243	203	446	279
Total	**459**	**654**	**363**	**1,017**	**558**

Data Source: *Health Facility records 2015 and 2017 and **partner Reports 2017.

It is important to note that some of the children in TAFU intervention areas especially those with lower level health facilities without ART programs for children were referred and enrolled in care at higher level health facilities mainly HC IVs and hospitals. For instance, in Napak District, most children from Iriri Sub-county were enrolled in care at Matanyi Hospital. Similarly, most children from South Division in Moroto were enrolled in HIV care at Moroto Hospital with well-established paediatric HIV services. Similar scenarios of children in target areas being enrolled at higher level health facilities were also common in Mityana and Mubende Districts. Across all study districts, such children and their caregivers however participated in TAFU support and VSLA groups in the target areas. Pooled analysis of changes in number of children in care at baseline and endline by district indicated that the number of children in HIV care had increased in all districts with more increase noted in Mubende, Mityana and Serere Districts (Figure 4).

[1] At the endline survey, some children in the TAFU target sub-counties were enrolled in HIV care at other health facilities mainly HC IVs and Hospitals. However some of these children/their caregivers benefited from peer supportgroups and village savings and loan associations.

Figure 4: Total Number of children on ART at target HCs by District baseline and endline



The number of children in icare in Napak and Moroto districts though increased remained lower than other districts as was the case at baseline. This is not suprising given the generally low HIV prevalence in the Karamoja region. Discussions with program partner staff and community resource persons revealed that some of the children had enrolled in care but got lost to follow up and were traced by the community resource persons and re-enrolled in care. Taken together at baseline a total of 456 children were in care in TAFU intervention areas. At end line study, this number increased to 1,017 implying that an additional of 561 children were supported by the program to enrol in care. Key informants and FGD participants especially in Serere, Mubende and Mityana distritcs noted that the number of children and women in HIV care had increased owing to the activities of TAFU program in target communities as some participants explained.

> *TAFU program has increased community awareness about paediatric HIV in the communities. As a result the number of women and children enrolled in HIV care has inreased at the target health facilities...(District Official Serere District).*

> *The most significant change caused by TAFU has been increase in the number of children in HIV Care. At the start of the TAFU program, we did did not know that these children are out there...but through community mobilisation and education on care and services for children living with HIV, we have started seing the numbers increasing...(PHA Network Mityana District).*

When TAFU had first come, we had 20 – 30 children in care. When the program trained and used VHTs today we have between 50 – 70 children in care at the HC (HW Bulera HC , Mityana District).

TAFU brought children on Board up to 14 years in care. Before, these were left unattended to... Now, many children are in care. Some families had very sick children. One child was staying with grandparents. She was very sick and a VHT came and took her to Health Center. The VHT sensitized the grandparents about the situation of the child, adherence to drugs and nutrition. And the girl is very fine now...(KI-Local leader Kikandwa, Mityana District).

The testing of children has increased, we were not doing it. Actually in the past years we had no clients. This has improved because of community dialogues that people got to know the importance of HIV testing (HW, Kidepo HC III, Moroto).

What is emerging from the above narratives is the fact that TAFU has made children living with HIV and their needs more visible in society and increased the number of children in care which was not the case before across all intervention districts. The numbers of children and women in care in Karamoja region increased but are few compared to other regionsboth atbaseline and endline surveys. This could be due to the generally low HIV prevalence in the region compared to other regions of Uganda.

With regard to eMTCT, the TAFU program also enhanced women's access to HIV testing services and linkage to eMTCT program. Over all 1,355 women were enrolled in HIV care for their own health and for prevention of mother to child transmission of HIV (1,228 in Mubende, 51 in Serere, 19 in Moroto and 57 in Napak) under the TAFU program.

Emerging Issues/Lessons

- TAFU interventions at health facility and community levels increased the visibility of children living with HIV and their needs.
- Through TAFU the number of children and women in HIV care increased.

3.2.4 Community and Couple Dialogue Sessions

The TAFU program promoted community and couple dialogue in homes where children and women are cared for in the five target districts. A review of program reports and discussions with project stakeholders revealed that dialogue meetings were an avenue to discuss issues generated during health facility information sessions and other concerns affecting community use of eMTCT and paediatric HIV services. Some of the issues discussed in community dialogues include: HIV stigma and how to overcome it, HIV disclosure, facts about HIV and eMTCT, ARV

adherence, gender based violence and implications for HIV care and drivers of HIV infection. In Moroto District, community dialogue meetings were guided by topics agreed upon by health workers, community and religious leaders on an issue of interest. For instance there is a general perception that 'a woman who delivers at home is couragious' and strong. This perception hinders health facility delivery and thus compromises eMTCT if the mother is HIV positive. To address this perception community stakeholders agreed on a topic for dialogue as 'a mother who delivers at a health facility is a loving and caring mother'. Dialogue meetings were jointly conducted by health workers, community and religious leaders, VHTs and expert clients who sensitised communities on HIV prevention, testing and treatment drawing from their own experiences and male involvement. Interviews and discussions with project stakeholders revealed that community dialogue meetings had contributed to increased community awareness on eMTCT and peadiatric HIV thus increasing service utilisation. Other endline study participants mentioned that community dialogue meetings had also contributed to reducing HIV related stigma as they explained.

> *Dialogue meetings especially involving use of expert clients have helped to dimistify HIV stigma. Some people who were not free to access HIV treatment for fear to be seen at treatment centres gained courage to come out and enrol in care after hearing testimonies from expert clients in community dialogue meetings ... (Community leader, Napak District).*
>
> *After community dialogue meetings the number of women attending ANC and delivering at health facilities increased in the target areas (HW, Moroto, District).*

In Serere, religious and community leaders would agree on actions to be undertaken based on the dialogue discussions. Community dialogue meetings were also credited for increasing male involvement in maternal and child health care.

In Moroto, TAFU implimenting partner (TAIP) supported communities and health facilities to purchase mega phones for use during community mobilisation and education. These are stored at the target health facilites and are accessed by communty leaders and other resource persons whenever required. Indeedcommunity, health facility and district officials appreciated the mega phones as one explianed.

> *TAIP/TAFU bought for us 10 mega phones which we use in community education and mobilisation. The mega phones also help us during health education talks. These days we no longer strain alot.... Even the district health team members, when they have a community health activity, they borrow the mega phones and return them to us (HW Moroto District).*

Health workers at TAFU supported health facilities noted that the mega phones were instrumental in mobilising community members for health education sessions on paediatric HIV and for HIV testing.

Couple dialogue meetings addressed issues such as communication especially among discordant couples, HIV status disclosure, PMTCT, nutrition, ANC, drug adherence and the importance of pediatric HIV care/treatment. VHTs worked together with the health workers to identify discordant couples from the health facilities and these were targeted for couple dialogue sessions. Some couples were able to disclose to each other as a result of these dialogues. In addition some couples formed savings and credit groups with scheduled meetings which further enhanced couple communication including talking about HIV prevention. The dialogue meetings were facilitated by the Health workers, religious leaders, VHTs and project coordinators. The community resource persons used flip charts with key messages on paediatric HIV and eMTCT to facilitate couple and community dialogue meetings. However, it was noted that all reference materials were in English thus a likely challenge for leaders, VHTs and other community resource persons with low levels of education to comprehend and pass on information effectively.

Emerging Issues/Lessons

- Couple dialogue sessions improved couple communication including on discolure of HIV status and talking about HIV prevention.
- Future programs should ensure that reference materials are provided in the language best understood by community leaders and volunteers to increase message reach and for better impact.

3.2.5 Families are strengthened economically by participating in VSLAs to better care for children's health

Evaluation findings revealed that TAFU program partners facilitated the formation of Village Savings and Loan Associations to strengthen the economic capacity of families of children and women affected and living with HIV.

Overall a total of 43 VSLA groups (Mubende 7, Mityana 3, Moroto 8, Napak17 and Serere 8) with a total of 1,008 members (an average of 25 - 35 members each) were formed and supported. Groups were received training in financial literacy, income generating activities, saving, loaning, record keeping and group management. In most places groups were given top-up funding of 250,000 - 500,000/ Uganda shillings to boost group funds available for loaning to members. In addition to this training, groups in Moroto also underwent training on 'Think Livelihoods' spread over 10 days. They were also trained on how to ask for support and were linked to other agencies for support. At the end of the training, one group in RUPA was found to be strong and did not require the limited support from TAFU. Thus 3 groups remained in the program and were linked to Action Africa Help-Uganda (AAH) together with UN Women for additional support. However, due to misunderstandings among members and mistrust of group leaders, only one group (Mango group from Campswahili Chini in South Division) received additional funding of 3.5 million Uganda Shillings (980 USD) and other support in form of rent for one year for a group store for their cereal business and purchase of furniture. In addition, the group received guidance from DCU-TAIP on business management. As a result, the group was involved in bulk buying and selling of cereal crops and profits were shared among members to meet the needs of their families. However, as the group business expands, more capacity

building especially in financial and business management skills will be required. Funding that had been earmarked for the other 2 groups was cancelled due to misunderstanding among group members and poor leadership. The implication here is that such groups still need support to build their members' and leadership capacity, close monitoring and guidance for them to grow and serve the intended purpose.

Across all the TAFU districts, VSLA groups were appreciated by members for enabling them to save and access credit whenever needed to start income generating projects and meet the health and education needs of their families including for children living with HIV. Group members across the TAFU study areas noted that VSLA groups gave them an opportunity to borrow money for transport to health care facilities for drug refills for themselves and their children. The ability of group members to meet the necessities of their children including clothing and food was strengthened.

In Serere, VSLA/Village Health Groups were an avenue for socialisation and support, health education and sharing experiences by VHTs and expert clients including on eMTCT and care for children living with HIV. Members of these groups also visit and support each other. On the benefits of VSLA/VHGs study participants noted:

> *The training on VSLA has helped us to put our savings to use and now we have started a business which is helping us. The training that was done gave us knowledge and we started savings and now we are doing business. We are self-driven and committed to development because savings started as self-initiative and then TAIP brought for us VSLA kits (*FGD men-Naoi village-Moroto).
>
> *The most significant change is the culture of saving because VSLA helps us to provide our families with food, clothing, school fees. Being part of VSLA groups helped us to start some businesses like brewing and this has reduced stigma from some of the community members (FGD VSLA Apeitolim-Napak).*
>
> *From the money I got from the project (VSLA), I managed to start a coffee business. Previously my children did not have clothes and shoes but when I got that money, I bought shoes and clothes for my children... I buy food for my family and now I look healthy... (FGD caregivers-Bulela H/C, Mityana).*
>
> *We have 6 groups and each group has been funded by CHAU with 500,000 and this has helped us to start some projects (FGD caregivers-Kiganda H/C, Mubende).*
>
> *VSLA groups are a source of information on health and care for children and some members have started income generation projects. Others borrow to meet the needs of their families such as medical care and school fees* (KI Leader VHG Serere).

Incoporating income generating activities in eMTCT and paediatric HIV care was a good innovation for mothers to address transport, food and lack of male involvement challenges. Women in groups supported by TAFU now have access to loans to start income generation projects to meet their treatment needs...(District Official Serere District).

Emerging from the above narratives is an indication that VSLA groups have contributed positively to improving the capacity of women and caregivers of children living with HIV to meet the needs of their families through borrowing and starting income generaton activities. As a results members were able to afford transport costs to health care facilities for women and children to access and remain in HIV care. The VSLA groups had also enhanced caregivers ability to meet the nutrition needs of children which are critical for optimal adherence to ARVs.

The main gaps in VSLAs in TAFU is that the training was not standardised. Besides, in Mubende and Mityana the training was for only a few days and was done for only group leaders who were expected to cascade the training to their members. This was unrealistic given the low levels of education of members. Besides, not training all group members negatively affected members trust and undertanding of group management and expectations. Whereas the program coodinators integrated training sessions in group meetings, in future it is important that whole group trainings on VSLA methodology are conducted to enable members to have a uniform start and understanding of the VSLA.

Two leaders from each group were trained at the start. The training combined VSLA leaders from Mubende and Mityana Districts for one day. At the begining, most group members did not have interest in VSLA I suspect because they were not well informed on the purpose of saving and how their savings were to be managed. CHAUstaff kept on training us every time we would meet to save and members increasingly appreciated the groups... (FGD VSLA Mubende).

In other districts, most VSLA groups were adequately trainied including on VSLA methodology, business skills and group leadership. In Moroto, group members also underwent the 'Think Livelihoods Training' which equipped them with a broader understanding of HIV within the broader context of livelihood opportunities and constraints. In Serere, the concept of community health insurance where members were encouraged to save for health and initiate vegetable gardens to improve clinic attendence and nutrition respectively were added to VSLA. In Napak VSLA group members were trained and provided with seeds to grow fast maturing fruits and vegetables. Overall, VSLA groups were helping to address the health information, transport and nutrition needs of children living with HIV and their families thus contributing to retention of children in HIV care. Discussions with TAFU partner staff and members of VSLA groups indicated that broadening the VSLA activities made such groups attractive to members.

Another limitation was that not all groups were given VSLA kits. This has negatively affected group running including record keeping. Given the widespread shortage of food, integrating nutrition interventions in these groups could also help. In Moroto, PAG-KIDEP supported some caregivers with short term maturing vegetable seeds for tomatoes, cabagges, sukuma and egg plants which were appreciated for being a source of food.

Emerging Issues/Lessons

- Though relatively new, VSLA groups were showing promise in meeting the needs of children living with HIV and their families particularly transport costs to health facilities and food.
- Training of VSLA groups was not standardised. In two districts (Mubende and Mityana) only 2 leaders per group were trained instead of training the whole group.
- The groups are still young and will require additional support to make them stronger including financial, creating linkages, business skills, ledearship development to assess impact on the lives of women and children living with HIV. But had contribited to meeting the needs of women and children including transport to health facilities and meeting nutrition needs.
- VSLA groups present a good opportunity to address other family needs such as information on HIV prevention and care for children and women living with HIV as well as training skills training including on agriculture to meet nutrition needs of family members.
- Groups still require support to improve potential for sustainable impact.

3.2.6 Empower Children living with HIV to deal with their status and adhere to treatment

The TAFU program supported formation of 16 peer support groups which directly benefited 859 children in HIV care in the target districts. The program conducted peer support meetings for children and those of their caregivers at health facilities. These groups were formed at health facilities with sufficient numbers of children mainly HC IVs and above. In collaboration with health care workers, VHTs and expert clients identified children and their caregivers and mobilised them to attend quarterly health facility based meetings. During such meetings, separate age appropriate sessions were conducted and facilitated jointly by health care workers, VHTs and expert clients. The key issues discussed include stigma, adherence, body changes and disclosure of HIV status. Concerns raised by children were discussed with caregivers and health workers. Peer support sessions were also used to identify children and/or caregivers who need further support for instance home visits and additional counselling.

> *Before TAFU came, there were no support groups or meetings for children living with HIV. With support from TAFU we started holding meetings for children living with HIV to*

discuss the challenges that they face and advise them. This has been very helpful in identifying children that need extra support... Some challenges children mention like failure to take ARVs because they don't have food, or being mistreated by caregivers we discuss them in caregiver meetings... (Health Worker Kiganda HC, Mubende).

During children support meetings we would separate them according to age. Those 9-14 years would ask questions and get their concerns at the health facility and at home addressed. Issues like being beaten when they miss taking their drugs (ARVs), lack of food ...VHTs would discuss these concerns with caregivers during home visits (PHA leader Mityana District).

TAFU has also improved the lives of our children since they give them soda and transport. This encourages the children living with HIV to stay in service which improves their health (FGD PMTCT mothers Bulela HC).

The major fear regarding support meetings for children relates to lack of facilitation when TAFU ends (drinks and transport refund for children and facilitators) as well as lack of play materials especially for younger children. In addition, given the increasing number of children in care, there are delays at the health facility and lack of a shed where to wait from and conduct peer support meetings. Lack of a shed for children was more pronounced at Bulera HC III in Mityana District.

When we come to the centre for medicine, we delay, we do not get what to eat and feel hungry. We come early and leave late at around at 4:00pm. When it is hot we suffer a lot as there is no shed where to wait from...(FGD children Bulera HC, Mityana).

The concerns of children about the need for awaiting shed at Bulera HC III were also re-echoed by health care workers and VHTs. While other health facilities also expressed need to improve infrastructure at health care facilities to better meet the care needs of children, the urgent need for a waiting shed was more pronounced at Bulera HC.

Emerging Issues/Lessons

- Peer support groups for children and caregivers were appreciated as avenues that helped to adress the concerns of children and those of their caregivers.
- As part of the project children were given transport refund and a drink. While these addressed felt needs of children, such support is sustainable beyond the project and its absence can negatively affect clinic attendence in future.

3.3. Mobilize communities in the 5 target districts to address barriers to testing, treatment and adherence and to create awareness around paediatric HIV treatment and the specific needs of children living with HIV

3.3.1 Community sensitisation on paediatric HIV care and PMTCT

The evaluation established that several activities were conducted to increase community awareness on the needs of children living with HIV. In all the project areas, partners conducted community dialogue meetings. These were meetings in which community members, leaders, health workers, VHTs, and expert clients jointly discussed issues affecting care for children and women living with HIV at family, community and health facility levels and generated/implemented actions to address the identified issues. Community dialogue meetings also helped to raise community awareness on issues of paediatric HIV. These were facilitated by project staff, expert clients, VHTs, community and religious leaders as well as health care workers. The composition of dialogue meetings helped to discuss and find solutions to issues at family, community and health facility levels regarding improving paediatric HIV care.

Table 6: Community dialogue meetings and people reached

Partner	No. Community Dialogue meetings	No. Leaders and community members reached
CHAU	82	1,884
HNU	17	414
TAIP	73	5,064
PAG	30	2,446
Total	**202**	**9,808**

Data Source: Program partner reports 2017

In Serere District, Village Health Groups and schools were other structures used in raising awareness about paediatric HIV testing and care. The baseline survey revealed generally limited community knowledge and conversations about HIV in the Karamoja region which hindered access and utilisation of HIV testing services as an entry point to HIV care for both adults and children. As a response, in Moroto District, community conversations and couple led discussions were key avenues for educating communities on HIV in general and paediatric HIV.
TAIP a TAFU partner in Moroto together with village health team members and health workers at target health facilities initiated community spaces where community members gathered and talked about issues affecting them including HIV within their village. The VHTs mobilised household members within their villages to meet at an agreed community venue. Health workers and community resource persons were available to guide the conversations. HIV counselling and testing services were provided and those found HIV positive were referred for care and followed up. Through this integrated community approach, community awareness and access to HIV prevention, testing and treatment services were enhanced in TAFU program areas. Overall, 5,917 community members participated in community conversations about HIV of whom 2,017 children and 1,954 adults received HIV testing services. Five adults (tested HIV positive) were found to be living with HIV and were linked to care while no child was found to

living with HIV. Couple discussions focused on improving couple communication on issues related to HIV prevention, testing, HIV status disclosure, HIV testing and care for children, use of eMTCT and other HIV treatment and care services if found to be living with HIV. Over 190 couples were reached with HIV information through this approach.

In Napak District, radio talks were another method used to mobilise and educate communities on paediatric HIV. In all community engagement activities, a range of topics were discussed including: HIV stigma and discrimination, the role of families and communities in paediatric HIV prevention, care and support; HIV testing, prevention of mother to child transmission of HIV and the importance of ARVs for people found to be living with HIV.

During the evaluation, most stakeholders mentioned that the various community engagement and sensitisation activities had increased awareness on paediatric HIV and care for children and contributed to reducing HIV related stigma even in Karamoja region where stigma was high during the baseline as explained.

> *The major contribution of TAFU has been increasing awareness about HIV in general and paediatric HIV. Many people are now aware. Community dialogue meetings made the message about HIV reach villages where we had not reached (District Official, Moroto).*
>
> *The project (TAFU) engaged many groups of people to sensitise on HIV. They used local leaders, religious leaders, VHTs and people living with HIV themselves...so we have seen more women living with HIV come out to talk about their HIV status and encourage others to test and enrol in care than before. Women these days don't fear to go to health facilities for ARVs compared to the situation before... (FGD religious leaders, Napak District).*
>
> *Stigma is still there but now it has reduced. You can now find people talking freely 'I have gone to pick my drugs...' This was not there before. The few people who would go for drugs would go hiding...(HW, Moroto).*

Emerging Issues/Lessons

- Community activities such as community dialogue meetings, community conversations (in Moroto), school activities (in Serere) and training of community and religious leaders increased the visibility of paediatric HIV prevention and care in the target areas.
- TAFU community activities improved caretaker Knowledge on HIV testing, prevention, treatment and care for children and women living with HIV.

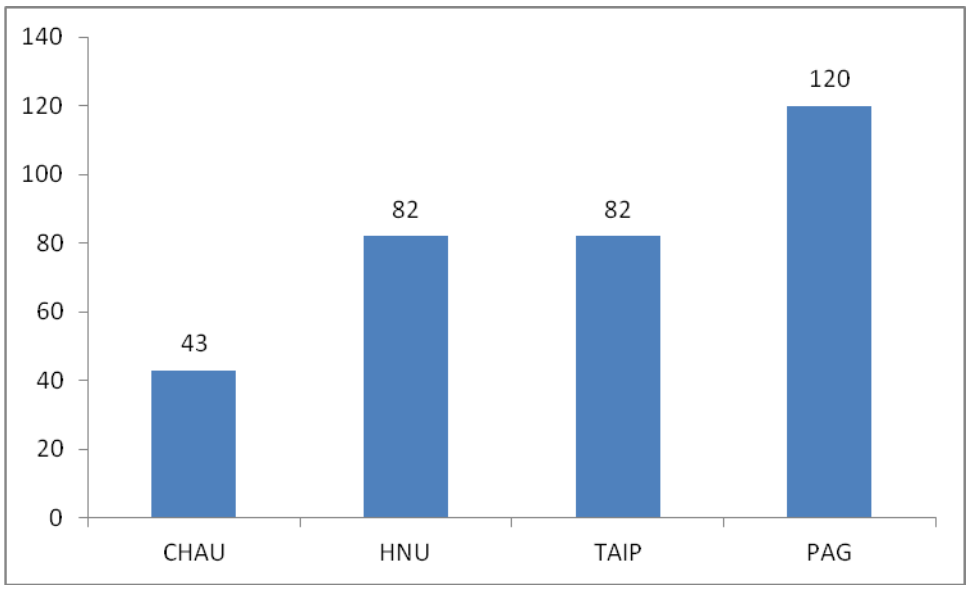
3.4 Strengthening tracing, referral and follow-up systems for HIV positive children especially at the lower levels of the health care system; and to improve coordination between village health teams and health centres.

TAFU program prioritised capacity building for community resource persons and health workers to strengthen the link between community and health care systems to identify and care for women and children living with HIV.

3.4.1 Capacity Building for Community Resource Persons

As part of the VHT capacity building, a VHT training manual and flip chart on paediatric HIV were centrally developed and used to conduct training of all community resource persons in the five target Districts. The VHT flip chart was distributed to VHTs and health workers to serve as a reference guide during household visits and community dialogues. The programme intended to train 200 VHTs. A review of program reports revealed that 327 (figure 5) VHTs/CoRPs were trained at the end of the project reflecting a higher level of achievement.

Figure 5: Number of Village Health Teams and Community Resource Persons Trained on eMTCT and Paediatric HIV by partner



Data Source: Program partner reports 2017

In addition, TAFU trained other community resource persons such as community and religious leaders, teachers and group leaders. The training focused on community mobilisation, eMTCT, paediatric HIV testing, treatment and care, referral mechanisms, follow up and home visits and data management among other topics. In Moroto District, six chapel councils (4 catholic and 2 evangelical churches) and 170 couples were trained on communication skills and HIV. In Napak District, 376 local and religious leaders were trained on paediatric HIV prevention and care. In Serere 40, Moroto 79 and Mityana/Mubende 29 community and religious leaders were trained.

Taken together the program trained and engaged 1,378 VHTs/Community resource persons (327 VHTs and 1051 other community resource persons) in activities geared at enhancing paediatric HIV prevention and care in the target areas.

Evaluation findings revealed that the trained local and religious leaders enhanced community mobilisation and education on paediatric HIV prevention, care and support for children and their caregivers. Evaluation findings revealed that community and religious leaders had started integrating paediatric HIV prevention and care messages in their work.

The trained community leaders were allocating time to VHTs and expert clients to talk about HIV testing, eMTCT and care for children living with HIV during community meetings. Religious leaders on the other hand integrated such messages in their sermons. Taken together, evaluation findings revealed that community interventions as part of TAFU had contributed to making paediatric HIV prevention and care more visible at community and family level, increased awareness about paediatric HIV and access to HIV testing and care services for children.

Variations were noted about the conduct of training of VHTs/CoRPs across TAFU areas. In Serere and Karamoja regions training of VHTs was done by TAFU partners with active involvement of health workers at target health facilities and relevant district health team officials. On the contrary in Mubende and Mityana VHTs were trained in Mityana which limited the participation of members of the DHT and health workers in training VHTs. This constituted a missed opportunity to foster an early working relationship with the DHT necessary for support supervision.

In all the districts, flip charts and other materials provided to VHTs were in English, yet most VHTs had low literacy levels especially in Karamoja region and thus could not effectively comprehend and use the messages on the flip charts during community health education sessions. As a result, most VHTs reported relying on what they could recall from the trainings and pictures on flip charts during health education.

Discussions with community members, VHTs and other stakeholders revealed that the VHTs trained under TAFU were actively involved in community mobilisation and education on paediatric HIV, conducting home visits and tracing clients lost to follow-up and linking them in care as explained.

> *TAFU trained VHTs on paediatric HIV. This project was unique because we have some health workers who have not yet been trained on eMTCT and paediatric HIV but the VHTs were trained and they have helped in mobilising communities for paediatric HIV care and prevention ...(District Official Moroto).*

The VHTs trained under TAFU are more active in community education, identifying and referring children suspected or known to be living with HIV to the health care system. Others even carry children to health centres...(HW Mubende District).

TAFU trained VHTs who refer children and mothers to health facilities. If any mother or child misses an appointment, VHTs help to follow them up because they know where these children and mothers come from (District Official Serere).

The implication here is that VHTs and other CoRPs in communities serve as a bridge between children/women and health care facilities. Discussions with VHTs revealed that the training had improved their understanding of paediatric HIV prevention and care. It was also noted that after training, VHTs were linked to health workers at health centres within their areas for joint planning and implementation, follow-up and continued support supervision. Health workers and VHTs were facilitated by TAFU to plan and implement joint activities such as health facility information sessions and community dialogue meetings; and regular sharing of information through client referral and follow-up forms, joint progress review meetings and reports. Joint planning, implementation and review of progress enhanced collaboration between health workers and VHTs in the provision of eMTCT and paediatric HIV services. Linkages and collaboration between VHTs and health care workers helped to improve identification, referral and support of children and women living with HIV in TAFU program areas.

The motivation of VHTs varied across the target districts. In Mubende and Mityana Districts, VHTs were given bicycles as well as monthly and quarterly allowance whenever they attended mentorship and review meetings respectively. In Serere, Moroto and Napak, they were given transport allowances during quarterly review meetings in which they submitted their activity reports or whenever they participated in other activities such as dialogue meetings, peer support meetings and health facility information sessions. In these districts, VHTs expressed a need for bicycles to ease reach to communities during mobilisation and household visits and support to form and build VHT associations to enable them mobilise additional resources on their own. The need to provide certificates, t-shirts and tools to use in the field such as gum boots and umbrellas were other items mentioned by VHTs that could enhance their motivation. There were concerns across all target districts that VHTs were likely to become inactive at the end of the program when they seize receiving transport allowances. This fear is valid given that in most settings in Uganda, the functionality of VHTs and their level of involvement in community health promotion activities is dependent on the availability of support from civil society partners.

Emerging Issues/Lessons

- VHTs and other CoRPs increased identification & referral of women & children for HIV testing, care & support with adherence with ARVs.
- In Mubende and Mityana, training of VHTs was done in one central place. This limited opportunity to involve DHT members and heath workers.

- Reference materials given to VHTs to use in community sensitisation were in English language and thus could not be comprehensively understood and effectively used.
- VHTs trained were few compared to the areas they were to cover. For instance, in Mityana and Mubende, only one VHT was selected at parish[2] level. Thus some villages were not reached.
- VHTs were engaged and motivated as individuals as opposed to exploring options to foster joint activities and motivation for VHT such as forming area specific VHT associations and encouraging them to start VSLAs and other joint activities likely to keep them together and functional beyond the project time frame.
- The training of community and religious leaders was done once, yet leaders expressed need for refresher training to address knowledge gaps in relation to HIV. Indeed, while the current guidelines recommend test and treat for all persons who test HIV positive most leaders talked to were not aware of this policy provision.
- Leaders in some areas were not provided with reference materials to use in community sensitisation. Where materials such as the flip chart were provided, such information was in English.
- Leaders were expected to integrate HIV sensitisation in their usual activities and thus were not facilitated. This limited the ability of leaders to reach communities with the needed health education messages.

3.4.2 Health care workers in HCII and III are capacitated to improve their services to women and their children exposed and living with HIV and their families

In all TAFU operating areas, health care workers were mentored on new paediatric HIV guidelines. The facility in-charges identified health workers directly involved in paediatric HIV prevention and care. The capacity of the identified health workers was assessed and capacity gaps in paediatric HIV management identified and were a basis for the mentorship. In most districts, mentorship was done by Ministry of Health HIV trainers within their respective districts (mainly members of the District Health Teams or from HIV implementing partners). The exception was in Mubende and Mityana Districts where mentorship was done by CHAU staff. The involvement of DHT and HIV implementing partner staff in mentoring health workers had an added advantage of providing additional technical support and follow-up during routine supervision visits. Overall, Health workers and District officials commended TAFU for enhancing health worker knowledge and skills to address paediatric HIV in target areas. Mentorship for health workers improved the care provided to children and women living with HIV especially by publicising the test and treat policy for all people diagnosed with HIV including women and children.

> *The program helped to train health workers involved in eMTCT and paediatric HIV care including orienting them on the test and treat policy for children and women in eMTCT. Other partners like Mildmay were training on HIV in general but TAFU focussed on children ....(District Official Mityana).*

[2]A parish on average has 4-6 villages making it difficult for one VHT member to adequately cover it.

The TAFU program also facilitated health workers from higher level health facilities (hospitals and HC IVs) to conduct Continuous Medical Education (CME) sessions for health workers at lower level health facilities mainly HC IIs and IIIs to address knowledge gaps and improve adherence to national HIV prevention and treatment guidelines. Discussions with health workers revealed that the mentorship and CME sessions had helped them to understand and use the eMTCT, ART and paediatric HIV care guidelines in their clinical and community education work. Thus improving the quality of care they provided to women and children.

Emerging Issues/Lessons

- Few health workers (2 HWs at most health facilities) were mentored as opposed to whole site mentorship for all health workers to increase understanding of eMTCT and paediatric HIV among all health workers.
- Members of the DHT were not involved in mentoring health workers in all districts yet they are critical in support supervision of health workers even beyond the project.

3.4.3 A coordinated system for tracing, referral and follow-up is created / strengthened between HCs and VHTs in the project areas

Evaluation findings show that program partners conducted quarterly district health coordination meetings in which progress was shared and issues that were requiring action from the DHT and those for advocacy were identified and a follow-up plan was agreed upon. Discussions with HWs and VHTs revealed that health workers, VHTs, expert clients and other community resource persons had a good working relationship and often conducted joint activities such as health facility based education sessions, joint house to house visits and joint progress review meetings. In situations of loss to follow-up for mothers or children, health workers generated lists of such children and gave them to VHTs for follow-up and support.

Program review meetings were also conducted with members of the district health team on quarterly basis. During these meetings progress reports were shared and actions requiring improvement at health facility and community levels from district officials were communicated by program staff. Some of the issues that were shared with the districts for action were: stock out of drugs at health facilities, few health workers leading to client delay at health facilities among others. Where stock out of drugs and HIV test kits occurred, DHT members redistributed drugs from other health facilities with adequate supply to those in need as a gap filler. District and higher-level health facility staff integrated eMTCT and paediatric HIV issues in their routine follow up and support supervision of health workers at lower level health facilities.

Emerging Issues/Lessons

- Review meetings were mainly limited to members of the DHT; involvement of non-health departments such as education, community development, probation, welfare and agriculture would enrich the outcomes of the meetings to the benefit of children and women living with HIV and VSLA group members.
- TAFU partners limited the role of district officials to sharing reports and review meetings yet their active participation in support supervision and jointly implementing some activities would add value to the program and improve chances for sustainability.

3.5 Build evidence and interest to upscale the TAFU approach

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

At TAFU program partner level, quarterly exchange learning meetings were used to share progress and for partners to learn from and support each other. This enhanced the quality of program implementation, monitoring and documentation of promising practices.

At health facility, sub-county and district levels, quarterly program review meetings and district HIV stakeholder coordination meetings, events to mark the international World AIDS Day and other stakeholder events were used to share updates on TAFU program approach, 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. As a result, the needed actions to enhance eMTCT and paediatric HIV were made visible to the wider audience in TAFU intervention areas and actions were taken to address some of the common challenges. For instance, district health teams and major HIV implementing partners such as Baylor, Mildmay supported health facilities to improve ordering of drugs and re-distributed ARVs and HIV test kits from health facilities with adequate supplies to those that experienced shortages. In addition, areas for linkages and collaboration among HIV implementing partners and TAFU partners were identified and partnerships established which improved the care and support women and children living with HIV received. For instance, in Mityana and Mubende, some of the adolescents living with HIV were linked to Mildmay and accessed vocational skills training. The Mityana District Forum of People Living With HIV/AIDS (MIFOPLA) advocated for 50 orphans and vulnerable children living with HIV under TAFU to receive food support from the government food donation program; in Napak, PAG-KIDEP linked some of the most vulnerable women and children living with HIV identified under the TAFU program to ACDI/VOCA and were supported with food to address their nutritional needs. In Moroto, TAIP linked VSLA groups formed under TAFU to AAH of which 2 were supported with additional funding to improve their businesses; in Serere HNU linked OVCs to the department of community development for support and follow-up.

The TAFU Model was documented and has been shared with several stakeholders within and outside Uganda. This has increased interest in the need to addressing linkages between community and health systems as a prerequisite to improve eMTCT and paediatric HIV services.

Partner organizations as well as the TAFU national secretariat continued to monitor implementation and document outcomes of the program. Lessons documented from the program were shared at different fora both in and outside Uganda mainly through presentations at conferences such as:

- AIDS 2016 in Durban
- Uganda National Paediatric and Adolescent HIV conference in Kampala 2016
- ICASA 2015, Zimbabwe.
- AIDS Impact meeting 2017

More so, 3 abstracts from TAFU program have been accepted for presentation at ICASA 2017 in December in Côte d'Ivoire and one abstract for the International AIDS impact conference 2017, in South Africa.

An article reflecting early insights and lessons from TAFU '*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* was published in Vulnerable Children and Youth Studies Journal, under open access. The continued sharing of key lessons from TAFU and the program model has potential for wider adoption of the model and thus likely to have more impact beyond intervention districts and Uganda. Indeed, through national and international advocacy efforts more partners such as the Ministry of Health, ELMA foundation and partners in Uganda; and the Paediatric AIDS Treatment for Africa also described as Paediatric – Adolescent -Treatment Africa (PATA) have gained interest in the model. The National Forum of People Living with HIV in Uganda (NAFOPHANU) has used lessons from TAFU to develop and redesign strategies and programs to address the needs of network members. For instance, the support groups formed under TAFU are being used to form or strengthen sub-county and district PLHIV networks and to advocate for improving interventions to identify and retain women and children living with HIV in care programs. Within Aidsfonds, the TAFU model has informed the development of a new eMTCT and paediatric HIV program being implemented in five Ugandan Districts (TAFU- II) and programs in Kenya and Zimbabwe.

Emerging issues

- TAFU model has been documented, shared and is influencing eMTCT and paediatric HIV interventions in Uganda and other settings
- The second phase of TAFU in Uganda and the new programs designed by Aidsfonds informed by the TAFU model in Kenya and Zimbabwe provide an opportunity to compare applicability and adoption of the model and lessons in strengthening community and health systems to better meet the needs of women and children living with HIV and to enhance paediatric HIV prevention.

3.6 Appraisal of the most significant contribution of TAFU Program

As part of the endline survey study participants were asked to mention the most significant change attributed to TAFU program. Overall, most study participants mentioned that the program created community awareness about paediatric HIV which motivated community members to take children suspected to be living with HIV for testing and those found to be positive to be enrolled and retained in care. Most study participants described TAFU as a project that was unique and the only one that targeted children as some informants noted.

> *We have had projects before that address HIV, but TAFU was unique in that it's the only project that I know of that came specifically to look for children living with HIV who* nobody *was looking for…(PHA official Mityana district).*

> *For me TAFU has been unique, its major contribution has been putting issues of children living with HIV on the agenda. Before this project, care for children living with HIV was mainly at hospitals and HC IVs. But with community mobilization and engaging district officials, care for children has been expanded and many people now take it as a priority than before (District Official Mubende).*

Other study participants noted that that through training community resource persons TAFU linked communities and health facilities for testing, enrolling and retaining children in care.

> *The program trained VHTs and other community leaders on identification, referral and follow-up of children living with HIV. For us we knew VHTs for other things… The trained VHTs have helped in mobilization of caregivers to take children for HIV testing and follow up for those in care. TAFU helped to link communities and health facilities… (District Official, Serere).*

In Karamoja region (Moroto and Napak) where HIV stigma and silence about HIV was very high at baseline, TAFU was described by most health workers, district officials and community members to have contributed to breaking the silence about HIV and creating awareness on the need for HIV testing and enrolling children and adults found to be living with HIV in care.

> *The major contribution of the program here in Moroto and Napak is making it possible for people to talk about HIV unlike before where it was like a taboo. People have been reached in communities during dialogues, health education talks… So if one found a child or mother living with HIV they know where to send them ….(HW Kidepo HC III, Moroto).*

Initiation of VSLA groups for women and caregivers of children living with HIV was another significant change mentioned across all the program areas.

For me starting VSLA has been a key contribution. Through VSLAs, women borrow and start income generating activities, others borrow money for transport to HCs for drug refills or to buy food...This was not there before TAFU came. Even having us as people from different religious groups get together and all talk about HIV in communities and in our places of worship was good and it has helped to increase the number of women enrolling in the program for prevention of mother to child transmission of HIV and care for children living with HIV ...(FGD Religious leaders Napak, District).

Other study participants noted that many people now ask health workers, local leaders and VHTs about HIV but also some people who feared stigma are increasingly coming out and starting on treatment. In this regard, TAFU has built the foundation for use of paediatric HIV prevention and care services even in Karamoja, a region where stigma and fear of a positive HIV results was more pronounced at the time of the baseline survey. Other significant changes mentioned are: initiation of support meetings for children living with HIV and their caregivers, training and facilitating VHTs and expert clients who mobilise and educate communities about paediatric HIV and conduct home visits to families with children living with HIV; and starting VSLA groups for women and caregivers of children living with HIV. Training and engaging expert clients in community mobilisation, sensitisation, tracing, referral and follow-up of mothers and children living with HIV was appreciated by most study participants. This was premised on the fact that unlike the general VHTs, expert clients often built on their experiences to support and encourage others especially those newly diagnosed with HIV.

Taken together, perspectives of study participants revealed that TAFU increased awareness especially on paediatric HIV care and created/enhanced support options at health facility and community levels for women and children living with HIV to enrol and remain in care.

3.7 Relationship of the TAFU Program and Other HIV interventions in target districts

The evaluation team sought stakeholders' perspectives on how TAFU program related with other HIV programs in intervention districts. At baseline, the major HIV implementing partners were: Baylor Uganda in Serere, Napak and Moroto Districts and Mildmay in Mubende and Mityana Districts. Most stakeholders noted that the activities of the major HIV implementing partners were largely facility based while those of TAFU were largely community based. Baylor and Mildmay mainly conducted staff training on HIV and TB treatment and management in general, provided data collection tools such as registers for use at health facilities; supported construction of infrastructure and equipping laboratories and recruitment of and paying for additional health workers involved in HIV care.

Baylor Uganda and Mildmay also recruited and facilitated peer mothers and fathers (one expert client at each health facility) based at health facilities to assist in HIV counseling, testing, distribution of drugs, weighting babies, conduct peer support meetings for mothers in eMTCT

program and follow-up to those who miss clinic appointments. Follow-up of clients who miss appointments was the main community activity of Baylor Uganda and Mildmay. The peer mothers and fathers supported by Baylor Uganda and Mildmay were few and had several health facility-based activities, health workers noted that the TAFU supported community resource persons played a critical complementary role in tracing and follow-up of women and children lost to follow-up but also referring women and children in their villages to health facilities for HIV testing and care (bottom up referral). In this regard, community resource persons under TAFU complimented efforts by health facilities, Baylor Uganda and Mildmay.

Indeed, most health workers and district officials characterized TAFU as largely being a community based program that involved mobilizing women and children for HIV testing, being initiated and retained in care using various community resource persons including VHTs, expert clients, local and religious leaders.

> *Mildmay does more of health facility and related system strengthening. They train health workers in general and ensure that the laboratories are functional and the drugs and other supplies are available. TAFU mobilizes children and women to use these services (District Official Mubende).*

> *When Baylor Uganda was active in Serere, it was mainly involved in equipping laboratories, providing buffer drugs and test kits or redistributing them to health facilities that experienced shortages. They were paying some volunteers to help in activities at the health centres and follow-up of clients at home if they missed clinic appointments. So they were like 90% health facility and 10% involved in community activities. TAFU is the opposite 90% community and linking to health facilities for HIV testing and care. So the two organizations were complimenting each other (District Official Serere).*

Emerging from the above narratives is the fact that most activities of Baylor Uganda and Mildmay tended to concentrate at health system strengthening while TAFU focused largely on community mobilization and community system strengthening. In this regard the two interventions complemented each other. In all intervention areas VHTs trained by TAFU had links with health facilities and would be notified to follow-up women and children in their areas who missed clinic visits. The TAFU program initiated VSLA groups for caretakers of children living with HIV to address economic barriers to seeking and remaining in care. TAFU also initiated support group meetings for children and their caregivers.

At some health facilities like in Kiganda HC IV in Mubende, these group meetings were jointly facilitated by TAFU and Mildmay (TAFU paid for porridge while Mildmay provided snacks for children during their clinic day). Also Mildmay bought play materials for children. In Serere

Baylor Uganda and District Health Team members were involved in training and mentoring health workers. At the time of the evaluation, Baylor had phased out of Serere, Moroto and Napak districts as a major HIV implementing partner while Mildmay was still the IP for Mubende and Mityana Districts. While TASO was earmarked to replace Baylor Uganda as a major HIV implementing partner in Karamoja and Eastern Uganda, at the time of the evaluation, gaps were noted in relation to stock out of HIV test kits and ARVs and low motivation among peers and staff who were directly being facilitated by Baylor Uganda. District officials also expressed lack of clarity on whether activities previously supported by Baylor Uganda would continue with the new HIV implementing partner and stressed the need for TAFU to continue and have a gradual phase out plan.

Emerging Issues/Lessons

- It is important to ensure that partners and district officials develop joint phase out plans before donor funded programs end to avoid disruptions in service delivery.

- While there were many areas in which TAFU and other stakeholder programs complimented each other, collaboration was based on informal and interpersonal relationships. Developing clear and formal strategies of collaboration and including having memoranda of understanding and developing joint plans could strengthen the complementarities of TAFU and other programs.

3.8 Challenges encountered during Program Implementation

The evaluation sought to document the challenges encountered in the implementation of the program. While a lot of progress has been made in addressing the challenges affecting paediatric HIV prevention and care seeking noted during the baseline, several challenges were still prevalent (matrix 1)

Household level challenges

At household level, the evaluation revealed that shortage of food, long-distance to health facilities, poverty, lack of money for transport to health facilities, drug side effects and lack of disclosure continued to affect children and women's use of HIV services in all TAFU intervention districts. At the time of the evaluation, due to sensitisation stigma was reported to be reducing, communities were now more aware of the need to take children for HIV testing, enrol those found to be living with HIV in care and support them to remain in care. The VSLA groups had started enabling members to meet the needs of children to attend clinic appointments through borrowing transport or from small projects initiated using loans from VSLA groups.

Food insecurity as a major challenge: Lack of food emerged as a major barrier to children and women's utilization of HIV care services across all the five intervention districts. During the

baseline, this challenge was mainly pronounced in the Karamoja region, but during the endline evaluation, it was in all districts. The widespread mention of lack of food in all program districts was attributed to the long dry spell that hit the country most part of last year (2016) culminating into a country wide shortage of food. Many study participants mentioned cases of people who had started and discontinued taking ARVs as one informant noted.

> *Lack of food is a major challenge to adherence to ARVS. Last year (2016) we lost three clients because of lack of food. Some clients are malnourished and find it difficult to swallow these drugs without food* (HW Napak District).

> *If the food in the family is not enough, children will not take drugs. Most of the vulnerable children out of care require food first and later drugs...(KI Serere District).*

> *Famine at household level due to long droughts has escalated poverty which affects food production and income. Many clients in care do not have enough resources to access good nutrition and other basic needs (KI-peer mother Kiganda HC).*

> *These are tough drugs, you feel sorry for people taking ARVs. They need food support. Sometimes it is the drugs killing people not HIV…some take ARVs on empty stomach (District Leader, Napak).*

Children in an FGD also added:

> *We lack enough food at home yet we have to take medicine and at times we take medicine and it burns our stomachs…so when there is no food we don't take ARVs (FGD, Children living with HIV, (Kyantungo HC, Mityana District).*

In all TAFU program areas partners had started including initiatives in VSLA groups such as encouraging/supporting group members to initiate vegetable gardens and linking families of vulnerable women and children to other programs by government and other non-government organisations to address the challenge of food shortage. Given the central role of food in the care for children and women living with HIV and its direct effect on adherence to ARVs, future programs should assess and address food security concerns.

Long distance to health facilities was another challenge mentioned as a barrier in access and use of eMTCT and paediatric HIV services. This made travel to health facilities for drug refills and routine tests costly in the context of poverty.

> *The distance between the health facility and some villages is too long, for example Kobebe village which has no mobile network to help them reach the health facility in case of emergencies and accessing PMTCT services. There is only one ambulance at the*

health center and the organizations which used to support the fuelling no longer do. For example CUAMM has withdrawn (FGD VHTS Kidepu H/C-Moroto).

TAFU program partners advocated for taking health services to health facilities nearer to the communities. However, this requires upgrading and accreditation of health facilities to provide integrated HIV services which was beyond program reach.

Fear of stigma

Whereas stigma was perceived to have reduced in all TAFU intervention areas, comparing baseline and end of project evaluation, most study participants mentioned that the fear of HIV stigma was still a major barrier to children and women's utilization of eMTCT and HIV care services. It was noted that women and children were worried of community members pointing fingers at them and identifying them as people living with HIV. In Karamoja region, where having HIV was perceived as 'near death' during the baseline (2015), this was starting to change due to widespread community sensitization and engagements including involvement of expert clients.

We have seen a great change when TAFU started. Before it was difficult to talk about HIV in this area but now, health workers, expert clients and VHTs have taken the messages on HIV prevention and care to villages where the program works. People have started understanding that if one has HIV he/she can take drugs and live. They have also seen expert clients who have given others hope. PMTCT women have seen or heard about HIV positive mothers who have given birth to negative children. So stigma has reduced… (KI Moroto District).

However, study participants noted that stigma is still prevalent especially among newly diagnosed HIV clients.

The challenge of stigma is worse for new clients. Newly tested clients fear to be seen at the health facility. There is a mother we tested last month and counselled her on the need to start ARVs immediately, but she did not want to start treatment for fear to be seen at the health centre. With the help of TAIP (TAFU Partner) we followed her up at home twice, encouraged her and she started ARVs today (HW Moroto District).

Many women do not come with their partners and say they will never tell their husbands. Women fear blame from their husbands for bringing HIV in the family... (HW Napak District).

Due to stigma we have a mother who has stopped coming claiming that she is already old so why take drugs... she suspended the drugs (KI Pingeri H/C, Serere District).

Findings show that children fear stigma and indeed some had experienced it at home, community and school settings.

> *At home I am fine, my mother and I take our drugs at the same time. When one forgets we remind each other. The challenge is at school, some children abuse me and say leave this one of HIV... (12 year old girl, Napak District).*
>
> *Children living with HIV are abused at home and in communities. Some are told – you are sick but why can't you die? They also face insults from neighbours – one adolescent brother said why do you give a person dying money? (FGD caregiver Napak).*
>
> *Some children are not told about their status due to fear of being stigmatized by fellow children (FGD PMTCT mothers- Matanyi hospital, Napak District).*
>
> *Sometimes, parents have discriminated their children. "You have already died. What will you help me?" Most children are in care of non-biological parents who have shown less care (FGD caregivers-Kasambya, Mubende District).*

What is emerging from the above voices is that stigma is still a barrier for women and children who test HIV positive to come out and access HIV care services. Interviews with children and caregivers revealed reservations and unwillingness to disclose children's HIV status to school authorities for fear that children will be stigmatized. Endline findings however revealed a promising trend of more people living with HIV going public about their HIV status even in settings like Karamoja where such a practice was limited. Use of expert clients in community dialogue and health facility education talks was said to be helpful in reducing stigma.

Matrix 1: Major challenges affecting Paediatric HIV prevention and Care by district

District	At family level	At community level	At health facility level
Moroto	- Lack of food - Poverty - Lack of transport - Drug reactions - Stigma & discrimination - Low levels of disclosure - Alcoholisms	- Persistent stigma & discrimination - Alcoholisms (accidental disclosure - Mobile populations	- Stock out of ARVs - Delays at health facilities - Lack of drugs for other sicknesses - Distance to the facility
Napak	- Lack of food - Poverty - Lack of transport - Lack of family support - Stigma - Alcoholisms	- Persistent stigma & discrimination - Alcoholisms - Mobile populations	- Stock out of ARVs - children given adult formulations) - Delays at health facilities - Lack of drugs for other sicknesses - Distance to the facility
Serere	- Long distances to health centres - Lack of transport - Lack of food - Stigma - Non-disclosure - Lack of family support - Side effects of ARVS - Domestic Violence	- Stigma & discrimination in the community - Stigma & discrimination in schools for children (nicknames)	- Stock out of ARVs - Delays at health facilities - Lack of interventions to address malnutrition - Lack of drugs for other sicknesses - Long distance to HCs
Mubende	- Lack of food - Stigma - Long distances to health centres - Lack of transport - Failure to meet other needs of children & women - Non-disclosure	- Stigma & discrimination in the community - Mobile populations	Stock out of ARVs Delays at health facilities Lack of drugs for other sicknesses Distance to the facilities Lack of support groups Lack of campaigns to test children
Mityana	- Long distances to health centres - Lack of transport - Stigma - Non-disclosure - Shortage of food	- Stigma & discrimination - Lack of support for other needs of children & their families	- Stock out of ARVs - Lack of interventions for to address malnutrition - Delays at health facilities - Lack of an appropriate waiting area for children (Bulera) - Distance to the facility

Low Male involvement and power imbalances between men and women

Study participants noted that the involvement of men in the PMTCT program and care for children living with HIV has improved but remains low and limits access and use of services for paediatric HIV prevention and care.

> *... We have two couples; the men are living with HIV and on treatment and they refused their wives to come for testing, when they (women) came and tested, the husbands refused them to come and pick drugs which is a challenge...(HW, Iriri HC, Napak district).*

> *Some men don't want to be associated with children living with HIV. When a child tests and is found to be living with HIV, some men abandon the child with the mother and marry other women. If the woman can afford food and transport to health facilities the child will be in care but if she can't afford the child may not afford or struggle to be in care (FGD Caregivers, Mityana District).*

Emerging from the above voices is the fact that low male involvement continues to limit women and children from accessing HIV services and requires more efforts to address it.

Shortage of drugs and other supplies remain a challenge. Stock out of HIV test kits and ARVs were key challenges. While most study participants mentioned that the supply of ARVs had improved in past 2 years, stock out was still a challenge partly owing to advocacy efforts by TAFU project partners. Stock out of drugs meant that women and children had to incur more costs and travelling time to the health facility to pick drugs which increased transport costs. In some instances, stock out of ARVs meant that some people especially children were given adult formulations as a gap filler. While this was rational in the eyes of the health workers, abrupt change of treatment interrupted with adherence as illustrated in the following case study.

> *I started ARVs but I reacted badly and agreed with my mother to stop the drugs. I stopped for about one year and a half. One day a woman from our village who also takes drugs came home and convinced me to come with her to the HC and re-start the treatment. I first refused. She came again two times and talked to my mother and she accepted. That time I was weak and sickly, so I also accepted to start treatment again. This time they gave me good drugs which were not like the first ones which made me sicker! I have been taking my drugs very well and I have no problem. I have also improved. But last time when I came they told me that my drug was finished. They gave me another type (adult dose) which I have feared to start. I fear that this drug may make me fall sick like the one I stopped at first. The drug that you are not used too is not easy to take. I asked the health worker he explained to me that I should break the tablet into two parts and take one half per day. But still I fear to take that drug. I will keep checking*

until when my drug has come... (Male child, 12 years in care at a health centre in Mityana[3]).

Another study participant one added:

Change of drugs gives us bad reactions and make us unwell. Drugs should not be changed all the time. They should maintain the drugs that we are used to (FGD men-Naoi village-Moroto District).

Changing for us medicine treats us badly. Some drugs make us feel like vomiting because our bodies are not used to the new ones... (FGD Children Kyantungo HC, Mityana District).

From the above narratives, stock out of ARVs meant complete shortage of drugs or lack of formulations for a particular age group. When health care workers prescribed similar drugs but differently packed (say adult dose to be used by children), such scenarios elicited fear of side effects and often interfered with adherence. While health workers explained and demonstrated to patients how to adjust the doses, those who experienced side effects in the past had their fears revived whenever they are given other drugs or similar drugs packed differently. Whereas TAFU partners continued to advocate for adequate and constant supply of ARVs and test kits to health facilities, the persistence of stock out of these critical supplies between baseline and endline reflects a need to further strengthen the health system.

Shortage of supplies was more pronounced in Karamoja and Eastern Uganda following the exit of Baylor Uganda as a major HIV implementing partner in the two regions. At the time of the endline survey, TASO had been earmarked to replace Baylor Uganda as the main HIV implementing partner but the package it was to offer was not yet known by stakeholders.

Difficulties to disclose HIV status: Like at baseline, most women found disclosure of HIV status to partners difficult for fear of losing support, experiencing domestic violence and to be chased away from their marital homes.

Some women fear to disclose their status. They don't want other people to know and this leads to missing medication since they cannot freely pick the drugs and take them (FGD-Caregivers Kasambya, Mubende District).

[3]Members of the research team explained and counselled the child to start taking the drugs and had a joint discussion with him and health workers at the facility. The health workers assured him that the drug had the same contents as the one he was taking and on its safety. They encouraged him not to fear it and to report to them any time he feels experiencing changes from the drug. Health workers also assured the child that they would return him to the drug he was used to as soon as they receive new stock.

Many children in care were equally not disclosed to for fear by caregivers that children will be hurt and will not keep the HIV status a secret.

> *Many caregivers fear to disclose to children their status. Even in caregiver meetings some insist that their children should not be told their HIV status. What we do is to keep encouraging them and telling them about the benefits of making children know. But it is not easy (HW Kyantungo HC, Mityana District).*

Programme Level Challenges

Limited coverage of the program – in all the project intervention areas, health workers, community leaders and district officials noted that the TAFU program had a limited reach. The program covered 2-4 sub-counties in each district yet even in the sub-county not all parishes were covered especially in Mubende and Mityana District. The low coverage limited program impact.

Few community resource persons trained. The VHTs supporting the program did not cover all parishes and villages in the target areas. For instance in Mubende and Mityana Districts one VHT was engaged per parish yet some parishes had 7-8 villages and this limited the effectiveness of the programme in such areas. Discussions with VHTs, HWs, District officials and program partner staff revealed that for better effectiveness, VHTs should be allocated a manageable area of operation.

Low levels of literacy especially in Karamoja Region limited the ability of community resource persons to document the activities they did and limited use of referral forms. Program partners conducted quarterly review meetings in which community resource persons described the activities they did and the changes they noticed in the lives of the women and children they served.

Documentation of referrals by VHTs to health facilities could not be computed: some VHTs provided verbal referral while some referral forms from VHTs were not honoured by health workers. At VHT level, low levels of literacy contributed to this challenge while at health facility, referral forms were perceived by some health workers as increasing work load in addition to the existing multiple registers and report forms health workers had to fill. The challenge was further compounded by the fact that referrals from VHTs were not integrated in health information management system and thus health workers were obliged to report on such data.

Mobile populations especially in Karamoja region and some parts of Mubende complicated continuity in care for women and children but also negatively affected the gains from community health education activities. TAFU partners and community resource persons in these areas mentioned that they often encountered many new community members during

health education activities implying that they often had to start again instead of building on earlier discussions.

Limited involvement of District and Sub-county officials especially at operational and supervision levels of the project threatens sustainability. It was noted that involvement of members of the District Health Team in the program was limited to sharing progress reports in quarterly meetings and sometimes opening and closing of program events. This constituted a missed opportunity to strengthen the program as one of the officials noted.

We know the culture of our people so we can add value if more involved in training and joint support supervision. If we had been involved more we could even follow up on the health workers, VHTs and support groups trained by TAFU beyond the project... (District Official Mubende).

It was noted that more involvement of District officials was limited by a lack of resources to facilitate their involvement such as providing for their transportation, refreshments and allowances. More collaboration with the DHT and other relevant Districts Departments such as community development, agriculture and education during support supervision, community dialogue could increase opportunities for learning and sustainability of program interventions and benefits.

Health facility challenges such as stock out of critical supplies like ARVs, drugs for other sicknesses and HIV test kits; long distance to health facilities and few health workers at health facilities translating into long waiting hours continued to hinder utilization of paediatric HIV prevention and care services in the TAFU target areas.

Multiple community needs and expectations such as need to be supported with school fees, food, transport and buying of some drugs that were not available at health units for opportunistic infections in the context of a limited program budget.

The short term nature of the TAFU program was also a challenge in itself. Most of the stakeholders viewed the programme as 'recent' only run for about 2 years and was thus perceived to be a program in the starting phase that required longer time of implementation to effectively measure its contribution in increasing demand and utilization of paediatric HIV prevention and care services. Indeed in some areas, community members were starting to know about the program and were starting to become open about community resource persons yet the program was ending (see box 1 for a summary of challenges).

Box 1: Summary challenges faced in TAFU program

- The program covered few Sub-counties and few health facilities in target districts
- Supported few volunteers at parish level and these were not adequately facilitated
- Some community resource persons were not given reference/information materials while those that were given materials were not in the local language.
- Low levels of literacy especially in Karamoja Region was a challenge for most community resource persons as they could not read or write.
- Migration of community members especially in Karamoja region and some parts of Mubende. This complicated continuity in care for women and children but also negatively affected the gains from community health education activities.
- Phase out of Baylor Uganda a major HIV implementing partner in Karamoja region and Serere District destabilized the delivery of HIV services including those for children and women. While TASO was to take over, when it is expected to start and the package it will offer was not yet known to stakeholders.
- Nutrition challenges in all districts especially in Karamoja region continued to make it difficult for women and children to adhere to treatment.
- Lack of interventions to address malnutrition at health facilities made it difficult to care for the most vulnerable children initially lost to care.
- The number of volunteers trained was small. In some areas such as Mubende, only one VHT was trained per parish.
- In Mubende and Mityana districts, training events were organized at central places sometimes in one intervention district. This made it difficult to involve relevant district officials in both districts.
- Documentation of referrals by VHTs to health facilities could not be computed: some VHTs provided verbal referral while some referral forms from VHTs were not honoured by health workers.
- Training and support of Village savings and loan associations was not standardised. In Mubende and Mityana districts only VSLA leaders were trained instead of whole group training.

3.9 Lessons Learnt

Building linkages between community resource persons and health facilities is possible and improves identification of vulnerable children and women and linking and retaining them in care. Effective training of community resource persons, providing them with reference materials in local languages, holding regular progress review meetings with stakeholders at district, health facility and community levels and motivating community resource persons are critical factors for success.

Use of village health team members who doubled as expert clients is a preferred way to reach people living with HIV including children. These draw on their experiences as a basis for providing support and encouragement. Training to enhance their knowledge including on ethical issues involved such as observing confidentiality is critical for success.

Support meetings for children and caregivers provide a unique opportunity for children and caregivers to share experiences, challenges and for them to support each other. Such meetings should be facilitated jointly by trained community resource persons together with skilled health workers. Support meetings of children should be age appropriate.

Active involvement of district health teams and officials from other departments such as community development and education in planning and implementation of activities including joint support supervision is key to promote program ownership and increase chances for success and sustainability.

Village Savings and loan associations provide avenues to address economic, health information support and other needs of families of children and women living with HIV. For them to be effective, appropriate training, equipping and regular monitoring are key.

Shortage of food is a major factor limiting women and children to enrol in HIV care and adherence to treatment. Programs aimed at improving HIV care for women and children should include actions that address strengthening food security especially for the most vulnerable families. Supporting families with training in agronomic skills and with inputs to grow their own food is key for program success.

Children living with HIV face stigma at home, community and school settings. Thus, activities that support children to build skills to respond to stigma such as peer support groups and individual counselling as well as creating awareness on the need to support children living with HIV in these settings including schools should part of program interventions.

4.0 Conclusions and Recommendations

4.1 Conclusions

The TAFU program strengthened the systems for tracing, referral and follow-up of (pregnant and breast feeding) women living with HIV and children living with HIV through training, support supervision and mentoring of health workers and community resource persons. Thus the program positively contributed towards strengthening the capacity of communities and health facilities in the five target districts with regard to elimination of mother to child transmission of HIV and paediatric HIV care. Program interventions were appreciated by community members, health workers and district officials.

The program initiated a community paediatric HIV mobilisation, sensitisation and follow-up component in the five districts. Although this component did not cover the entire districts it has been appreciated by community members, health workers and district officials a mechanism for increasing access to paediatric HIV prevention and care services in the target districts. In the two districts of Karamoja region where HIV stigma and silence about HIV were very high at baseline, a foundation for families and communities to talk about HIV prevention, testing and care especially for women and children has been created through building community and health care systems and linking them.

The TAFU program initiated targeted village savings and loan associations (VSLA) for women and caregivers of children living with HIV in the target communities. Overall, 1,008 women living with HIV and caregivers of children living with HIV have been linked to VSLA groups. While these groups are relatively new, they have started addressing the economic challenges faced by families of children and women living with HIV. The VSLA groups are a source of credit for members to start businesses for income generation, meet family priority need such as health care, education, feeding and other needs related to the care of children, provide space for psychosocial support among members and for raising awareness on paediatric HIV care and treatment.

Overall, there was increased utilization of eMTCT and paediatric HIV services especially in Mubende, Mityana and Serere Districts. Whereas the numbers of children in care in Karamoja did not increase substantially, the program has built the foundation for paediatric HIV prevention and improving care through building community and health care systems and linking them. The TAFU program increased community awareness about paediatric HIV and contributed to reducing HIV related stigma. The program has popularised paediatric HIV care needs in the target areas and has created the foundation for identifying children and women

living with HIV especially the most vulnerable, linking them to health care facilities and supporting them to remain in care.

4.2 Recommendations

Recommendations for TAFU 1

Develop and implement a low-key follow-up phase at least for at least 12 months. TAFU partners in Napak and Moroto Districts which are not part of the second phase of TAFU program should develop and implement at least one-year phase-out plan to facilitate smooth phase-out of target communities and improve chances for program sustainability. The low-key follow-up phase will enable partners to strengthen key structures such as VSLA groups, VHTs, Church groups and improve collaboration with relevant district departments for sustainability.

Facilitate learning from TAFU 1- For partners in Eastern and Central Uganda, during implementation part of the TAFU II program, it is important that follow up plans are developed and implemented to ensure continuity of key interventions initiated under the first phase of TAFU. Community structures and health facilities that participated in TAFU I should be used for exchange visits and learning by structures in TAFU II.

Active linkage of TAFU with the DHT, Community development, education and agriculture departments should be strengthened especially regarding the activities of VHTs, VSLA/VHG and support groups for women and children.

Support families of children affected by HIV to enhance their capacity to meet their nutrition needs. 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. These gardens should be intended to produce fruits and greens for home consumption and surplus for sale. This approach has potential to boost their capacity to save with VSLA/VHGs.

Document case studies of project successes: Document the number of children living with HIV behind VSLA groups and how caregivers being part of these groups improve care for children.

TAFU II and Other Programs

More involvement of the target district officials beyond sharing reports is preferred and recommended. District officials including members of the District Health Team and officials from other relevant departments like community development, education, agriculture should be involved in joint planning and implementation of activities such as training of health workers, community resource persons, VSLA groups and conducting joint support supervision.

This will aid addressing emerging issues in a timely manner and to ensure ownership and sustainability of program interventions and benefits beyond the program time frame.

Conduct whole site training at health facilities to benefit all health workers involved in the delivery of paediatric HIV prevention and care services.

Address nutrition challenges in relation to HIV especially regarding children. Future **programmes should consider addressing nutrition challenges** at health facility levels for severely malnourished children during the critical phases of engaging with care. Such interventions should include advocacy for the provision of ready to use foods for severely malnourished children at all HIV care sites. At family and group levels, activities that promote food security and improve the nutritional value of household food should be promoted. Such interventions should include support and promotion of backyard and kitchen gardens and educating caregivers and community members on how to prepare nutritious meals and balanced diet among others particularly using locally available foods.

Train community resource persons within their districts in partnership with relevant district officials. For instance, the district VHT coordinators and some health workers in areas of operation of VHTs should be involved in the training.

Support Community resource persons to form area specific associations and devise mechanisms to provide association/group based support to enable them attract support to meet needs beyond what TAFU program can provide.

Conduct standard training for all VSLA members, provide VSLA kits and support VSLA groups to register as associations at Sub-county and district levels to open more doors to access additional support. VSLA groups should also be trained and supported to address nutritional needs of their families.

Engage and build the capacity of District Networks of people living with HIV in community mobilisation and education about the need to test children suspected to be living with HIV and link them to care. Exchange visits to strong networks like the one of Mityana should be promoted for learning.

<u>District and MOH level recommendations</u>

Health facilities should further be strengthened with more staff and constant supply of drugs and sundries. Attempts should be made to ensure continuation of support supervision by the district health team.

The TAFU program initiated a community mobilisation, support and follow-up program in the five districts. This component should be integrated in the ongoing discussions to restructure

VHTs and other community health promotion programmes. **Documentation of referrals and other activities done by VHTs should be strengthened.**

END

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