# Community intervention model for reaching all children exposed to HIV

## Experiences from the Towards an AIDS Free Generation in Uganda programme

aidsfonds

Towards an AIDS free generation

## Colofon

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## List of abbreviations

| | |
|---|---|
| **ART** | Antiretroviral treatment |
| **CBO** | Community based organisation |
| **CHW** | Community Health Worker |
| **CoRP** | Community Resource Person (includes people living with HIV, local and religious leaders and teachers) |
| **CSO** | Civil society organisation |
| **CSS** | Community Systems Strengthening |
| **eMTCT** | Elimination of mother to child transmission |
| **HCW** | Health Care Worker (health facility based) |
| **NGO** | Non-governmental organisation |
| **PLHIV** | People living with HIV |
| **PMTCT** | Prevention of mother to child transmission |
| **TAFU** | Towards an AIDS Free Generation in Uganda programme |
| **VSLA** | Village Saving and Loans Association |

## Key definitions

**Community Systems:**
According to the Global Fund to fight AIDS, Tuberculosis and Malaria community systems[1] are community-led structures and mechanisms through which community members and community-based organisations and groups interact, coordinate and deliver their responses to the challenges and needs affecting communities. Community systems are made up of community members, formal and informal community organisations and networks, and other civil society organisations. Community system structures and mechanisms have a unique ability to identify, understand and respond to community needs.

**Community Systems Strengthening:**
Community Systems Strengthening (CSS) is an approach that promotes the development of informed, capable and coordinated communities, community-based organisations, groups, networks and structures. CSS involves a broad range of community actors, enabling them to contribute as equal partners alongside other actors to the long-term sustainability of health and other interventions at the community level. The goal of CSS is to achieve improved health outcomes by developing the role of key affected populations and communities and of community-based organisations in the design, delivery, monitoring and evaluation of services and activities related to disease prevention, treatment, care, support and other health challenges.

# 1. A community intervention model for reaching children exposed to HIV

This document describes how the Aidsfonds-initiated programme Towards an AIDS-Free Generation in Uganda (TAFU) tested and further developed a community intervention model. Based on the positive results achieved so far, this model should be adopted and implemented by others within Uganda and further afield. The TAFU programme has reduced HIV infection rates among children and increased the number of children living with HIV on treatment in specific districts in Uganda. The programme provides a valuable working example of the Community Systems Strengthening (CSS) framework approach developed by the Global Fund to fight AIDS, Tuberculosis and Malaria.

### The context in Uganda

Uganda has made steady progress in addressing HIV, including scale up of services for elimination of mother to child transmission (eMTCT), and care for adults and children living with HIV. Routine HIV testing is integrated into most maternal and child health services, with over 95 percent of pregnant women attending antenatal services tested for HIV.

At the start of the TAFU programme in 2015, 140,000 children aged 0-14 years were estimated to be living with HIV in Uganda[2] of which only 42 percent were on treatment. The 2016/2017 national population based HIV impact assessment[3] estimates that 95,000 children aged 0-14

**"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..."**

– Key Informant, Moroto District

were living with HIV; 62 percent were on antiretroviral treatment (ART)[4]. Despite this progress large numbers of children living with HIV are still not identified, test results are not reaching families and many drop out after enrolment into care. When the programme started, most paediatric HIV prevention and care services were based at health facilities and unable to access hard-to-reach children to enrol them in care. Linkages between health care facilities and communities were weak and strategies employed to address this were not implemented at scale. In addition, systems for follow-up, tracing and referral of women and children living with HIV between health facilities and communities were lacking or weak leading to high rates of loss to follow up of patients.

## How the community intervention model is addressing the gaps

To reach ALL children living with and/or affected by HIV, the gap between health facilities where much of the care is provided, and the communities, where children are conceived, born and cared for, needs to be bridged. The community intervention model introduced through the TAFU programme was designed to strengthen the role of communities in programmes targeting children affected by and/or living with HIV, and at the same time bridge the gap between the community systems and the health systems.

TAFU's phase 1 evaluation[5] in 2017 demonstrated that the programme: effectively created linkages between communities and health facilities; built the capacity of community resource persons (CoRPS) such as teachers and religious leaders to raise awareness on paediatric HIV prevention and care; and mobilised support for children and women, addressing social barriers they have faced in accessing HIV services.

By increasing the number of children living with HIV identified, on treatment and retained in care, the TAFU programme contributes to the global Start free, stay free, AIDS free framework[6].

## Structure of this paper

This document sets out to share learning from the TAFU programme, now that it has been implemented for three years. It is aimed at programme implementers, policy makers and donor agencies who seek an intervention model that can effectively build the community role into their programmes and strengthen the linkages between community actors and healthcare providers, with the aim of finding the missing children living with HIV, enrolling and retaining them in care.

Chapter 2 provides a summary of the TAFU programme and how it fits into the continuum of HIV care. Chapter 3 explains how the community intervention model

relates to the six core elements of the Community Systems Strengthening (CSS) framework. Chapter 4 considers the scale up and replication of the model, presenting the TAFU programme's key results so far, success factors, lessons learnt and, based on these, recommendations for widespread take up of the model.

**"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

# 2. The TAFU programme: implementing the community intervention model

The four-year Aidsfonds-initiated TAFU programme aims to ensure that all children, pregnant women and mothers living with HIV are enrolled and retained on treatment, and that new infections among infants are eliminated, in the programme districts in Uganda.

**The TAFU programme goals are to:**

- ✓ Reduce the number of new HIV infections among infants and increase the number of HIV-positive children (0-14 years) on treatment;
- ✓ Test and further develop the community intervention model.

**Key objectives are to:**

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

The TAFU programme started in 2015 in five rural Ugandan districts (Serere, Moroto, Napak, Mubende and Mityana). The second phase[7] began in July 2017 and is due to end in June 2019, working in Mubende, Mityana, Kyenjojo, Ntungamo and Soroti districts. In Mubende and Mityana the programme worked in different subcounties to those targeted the first phase. The programme districts were selected using several criteria:

- a 'high paediatric treatment scale-up potential';
- complementarity potential with the HIV implementing partner operating in that district;
- potential to build on efforts of the local partner organisations;
- districts in three regions to be able to compare approaches between regions;
- proximity of some districts in relation to each other, for the purpose of efficient implementation (3 geographic clusters).

The TAFU programme addresses a complex set of social and economic challenges existing in communities including poverty and stigma. The key elements of the programme's approach are summarised in Table 1.

## Table 1: TAFU programme approach

| The TAFU programme uses the following strategies to address barriers in the targeted communities: |
|---|
| **Address socio-economic barriers by working with families to:**<br>• create awareness of paediatric HIV care and support<br>• address stigma at household level<br>• facilitate economic empowerment<br>• assist families in coping with household level barriers |
| **Address structural barriers at community level, by working with community systems to:**<br>• create awareness of paediatric HIV care and support<br>• address stigma within community systems<br>• initiate and strengthen peer support groups<br>• build capacity of Community Health Workers[8] and other Community Resource Persons to trace, support, refer, follow-up children living with HIV |
| **Create strong coordinated system of tracing, identification, care, referral and follow-up for children living with HIV by working with CHWs and lower level health facilities to:**<br>• improve coordination between Community Health Workers and Health Care Workers<br>• create and strengthen linkages between health facilities and community systems<br>• build capacity of Community Health Workers to become linking pin between health facilities and communities<br>• advocate to health facilities, districts, government to use other entry points to find and link HIV positive children to health care and support |
| **Advocate and align activities with other relevant health partners to improve the quantity and quality of service delivery at health facility level eg training of health workers in paediatric ART and counselling.** |

**The programme's key interventions are:**

- ✓ Training and mentoring of Community Health Workers (CHWs), other Community Resource Persons (CoRPs) and Health Care Workers (HCWs) in paediatric HIV care and support, in creating linkages to enable complete trace-referral-enrollment-follow-up loop and in data recording and documentation;
- ✓ Household visits by CHWs and other CoRPs to educate people on paediatric HIV care and support, refer exposed women and children for testing and treatment, link them to other community support systems, and follow-up on HIV care;
- ✓ Peer support groups for children and their caregivers where they can share experiences and barriers and can help each other in treatment adherence;
- ✓ Village Saving and Loans Associations (VSLAs) to help caregivers meet nutritional,health care and other needs of children;
- ✓ Community education in paediatric HIV to reduce stigma and mobilise support for childen and their caregivers.

**How TAFU integrates community actors**

The TAFU programme demonstrates how to link community-based health promotion and mobilisation activities with services provided by the health care facilities. Key to the programme is the close interaction between health facility-based HCWs, CHWs and other CoRPs who include people living with HIV, local and religious leaders and teachers. This integrated approach enables a complete trace-referral-enrollment-follow-up system.

At the start of the TAFU programme, community systems were identified and supported to serve as bridges between communities and health care facilities. These community systems include CHWs, other CoRPs and community groups (churches/ mosques, VSLAs, institutions such as schools, networks of people living with HIV (PLHIV) and other community-based organisations). The community systems provide a valuable feedback loop for improving the quality of health services and can serve as a basis for advocacy to improve the quality and delivery of services.

As Figure 1 illustrates, the TAFU community intervention model involves different actors working closely together to deliver an effective tracing, referral and follow-up system for children affected by HIV. The CHWs and other CoRPs play a central role by acting as the linking pin between communities and health facilities. Their role is to trace the families and children at risk of HIV in their


**Figure 1: TAFU community intervention model**

homes, ensure that they are tested for HIV and if needed refer them for HIV treatment and support. Once they are in the health care system, the CHWs follow up with the women and children exposed to HIV to ensure they receive ongoing support. The CHWs and other CoRPs also discuss socio-economic challenges that these women/children may be experiencing and link them to other community support systems, such as VSLAs, to meet these needs. To address stigma and discrimination the CHWs work with local andreligious leaders and schools. Because of their unique position bridging the community and health system, the CHWs can ensure that relevant information from the clients and communities reaches the facility-based HCWs, which in turn improves the facility-based care. In this way the CHWs are essential to completing the referral-loop.

## TAFU implementing partners

**The TAFU programme is implemented by the following Ugandan non-government organisations (NGOs):**

- ✓ Deliverance Church Uganda – The AIDS Intervention Programme in Moroto district (2015-2017)
- ✓ Pentecostal Assemblies of God – Karamoja Integrated Development Programme in Napak district (2015-2017)
- ✓ Health Need Uganda in Serere district (2015-2017) and Soroti district (2017-2019)
- ✓ Community Health Alliance Uganda in Mubende and Mityana districts (2015-2019)
- ✓ The National Forum of People Living with HIV/AIDS Networks in Uganda (2015-2019)
- ✓ Appropriate Revival Initiatives for Strategic Empowerment in Ntungamo District (2017-2019)

Funding and technical support is provided by Aidsfonds.

The programme builds on the expertise and experience of the TAFU implementing partners in: community mobilisation; providing community-based health services; linking families to existing health facilities and services; addressing stigma; and creating an enabling environment for greater access to services for the community, including PLHIV.

**Links with other stakeholders**

TAFU is implemented by local partners (see BOX) in collaboration with district health departments and Uganda's Ministry of Health (AIDS Control Programme). It further links with and builds on the experience and expertise of existing HIV implementing partners in the districts. Beyond direct programme support, collaboration with other governmental departments and ministries of education, community development, child protection, gender and agriculture as well as with other civil society organisations (CSOs) is critical in meeting the needs of children and women living with HIV and their families. For instance, the evaluation of the first two years of the TAFU programme revealed that VSLAs, through their links with other governmental departments such as community development,

**"The 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 increased at the target health facilities."**
– District Official, Serere District

had accessed additional training and supplementary funding for peer group activities. Community development, probation and welfare officers have also played a crucial role in child protection.

**TAFU interventions along the continuum of HIV care**

Strengthening the capacity of CHWs and other CoRPs is key to ensure that they are equipped to enable women and children

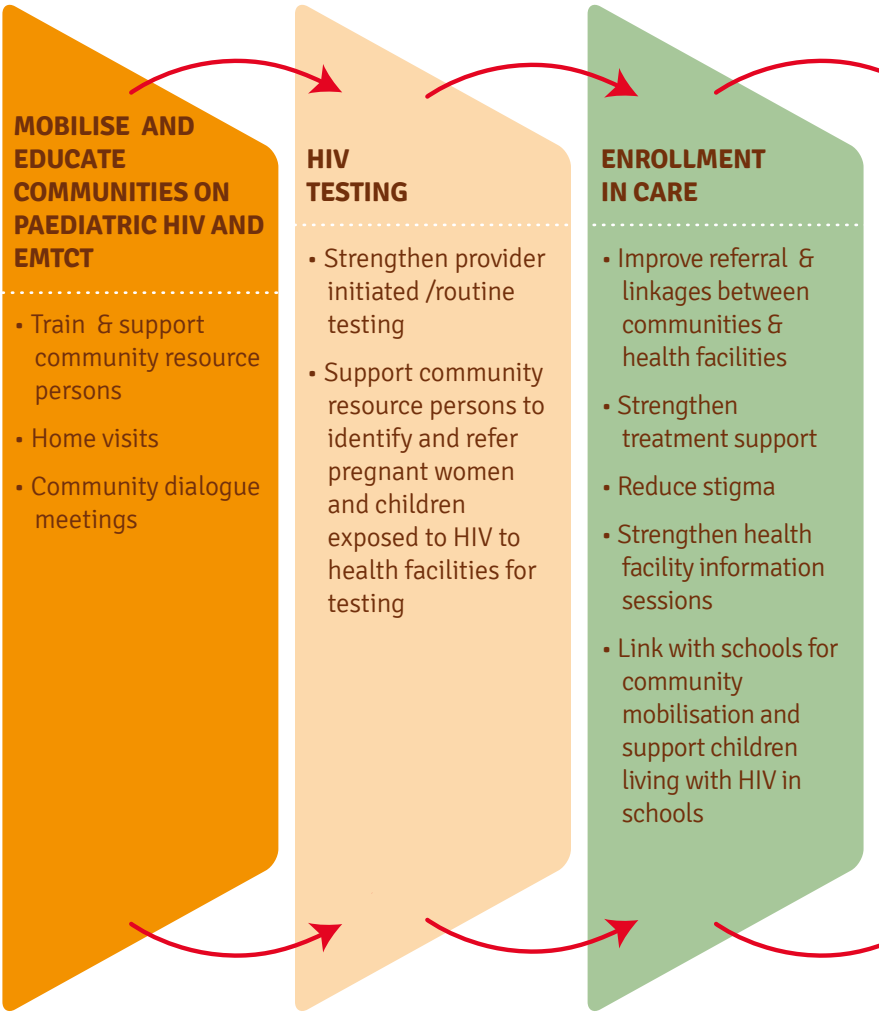
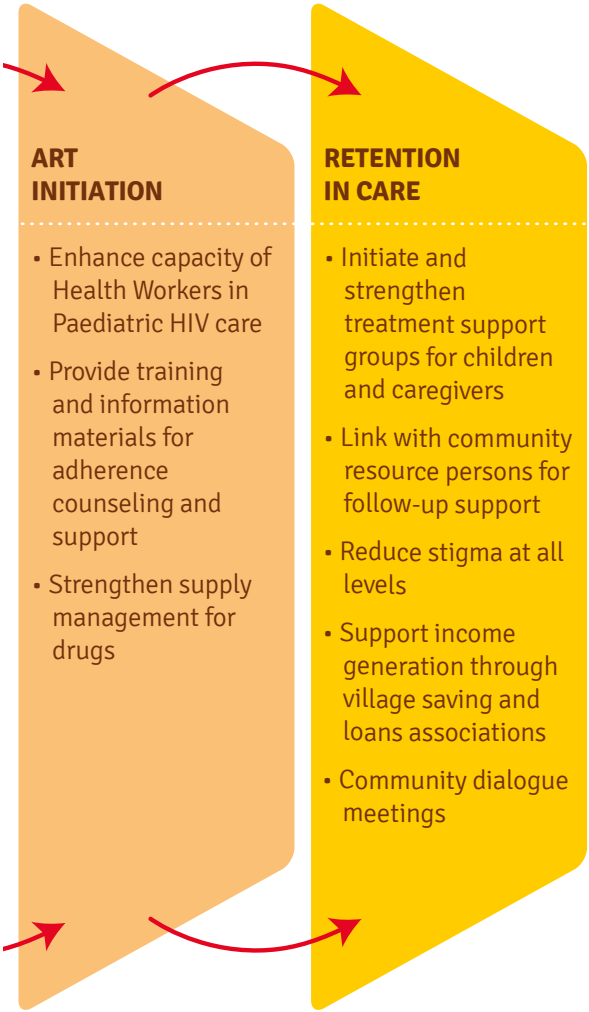



**Figure 2 : TAFU initiatives along the continuum of HIV care**

iving with HIV to access health services right along the continuum of HIV care – from prevention to treatment and follow-up support. Figure 2 describes the different stages of interventions implemented by the TAFU programme through this continuum. Chapter 3 describes these interventions further, including the capacity-building component of the programme.



# 3. TAFU community interventions and how they relate to the Community System Strengthening framework

The Community System Strengthening (CSS) framework was advanced by the Global Fund to fight AIDS, Tuberculosis and Malaria in collaboration with several international stakeholders[9]. It provides clear guidance for building effective and sustainable investments in communities, community-based organisations (CBOs), networks and other community structures to improve health outcomes.

The CSS framework can help to formulate a programme that enables community actors to play an effective role alongside health, social and other community systems, as they have the ability to interact with affected communities, provide services in a timely manner and advocate for improved programming and policies. Regarding HIV, the CSS framework recognises the critical role of communities in provision of HIV prevention, treatment, care and support services as well as advocacy for improving the delivery of health services. To have the desired impact, CBOs and networks must have effective and sustainable systems to support their activities and services.

**The six core components of CSS are:**

- ✓ Enabling environments and advocacy
- ✓ Community networks, linkages, partnerships and coordination
- ✓ Resources and capacity building
- ✓ Community activities and service delivery
- ✓ Organisational and leadership strengthening
- ✓ Monitoring, evaluation and planning

Table 2 summarises the key TAFU interventions and how they relate to these six core elements of the CSS framework.

**Table 2: Summary of how TAFU interventions are linked to the core components of the CSS framework**

| Core components of CSS framework | TAFU intervention |
|---|---|
| **1. Enabling environments and advocacy** | • Conduct participatory baseline and end line surveys<br>• Train HCWs at health facilities on paediatric HIV<br>• Conduct participatory community dialogue meetings<br>• Organise joint stakeholder project review meetings |
| **2. Community networks, linkages, partnerships and coordination** | • Build networks and linkages of CHWs and other CoRPs<br>• Map out and link key CoRPs, community groups and organisations relevant to paediatric HIV prevention and care<br>• Bring different actors together to strengthen tracing, referral and follow-up support for children living with HIV |
| **3. Resources and capacity building** | • Train CHWs and other CoRPs in paediatric HIV care and support<br>• Tap existing resources for building capacity of CHWs, CoRPs, and health facility staff<br>• Facilitate acquisition and distribution of updated guidelines and information resources on eMTCT and Paediatric HIV care<br>• Provide CHWs and CoRPs with means of transport and reference materials to reach out, engage, educate and support communities<br>• Train and supplement VSLA's efforts to meet the financial needs of women and children<br>• Pay salaries of staff directly involved in programme implementation<br>• Share expertise and tools among programme partners |

| Core components of CSS framework | TAFU intervention |
|---|---|
| **4. Community activities and service delivery** | • Work with CHWs and other CoRPs to conduct outreach, home visits, health education so that they can identify, refer, and follow-up women/ children living with HIV<br>• Address stigma as barrier to women/children's enrollment and retention in HIV care<br>• Work with VSLAs to address financial needs of women/children living with HIV<br>• Link with schools/teachers for community mobilisation and support |
| **5. Organisational and leadership strengthening** | • Conduct quarterly programme partner review and exchange meetings<br>• Share tools, guidelines, training manuals and expertise among programme partners<br>• Coordinate effectively between CHWs, CoRPs and health facilities |
| **6. Monitoring, evaluation and planning** | • Conduct baseline and end line assessments and develop monitoring and evaluation framework<br>• Disseminate results from baseline and end line assessments at district and national levels<br>• Adapt existing data collection tools and develop tools for specific programme indicators<br>• Train CHWs, CoRPs and health care workers in data collection |

# 1. Enabling environments and advocacy

- Conduct participatory baseline and end line surveys
- Train HCWs at health facilities on paediatric HIV
- Conduct participatory community dialogue meetings
- Organise joint stakeholder project review meetings

**TAFU programme experience**
At the start of the programme, a baseline survey involving a wide range of local stakeholders revealed gaps at health care facilities. These gaps related to staff knowledge and skills in the management of paediatric HIV, lack of guidelines and regular occurrence of stock outs of critical supplies for prevention of mother to child transmission (PMTCT) (mainly drugs and HIV test kits) and treatment of children living with HIV. For this reason, focusing only on CSS would not deliver the intended outcomes. Thus, the programme trained HCWs at health facilities in collaboration with major HIV implementing partners in paediatric HIV care as well as supplies management and forecasting.

This training of HCWs has led to an increase in the number of health facilities providing paediatric HIV services but also the number of HCWs with skills in paediatric HIV care. Evaluation findings revealed that training that involved all HCWs – rather than selected ones – was more effective in building their capacity.

Through the TAFU programme community actors such as CHWs and other CoRPs were engaged in conducting home visits, health education, community dialogue and sensitisation meetings to change community social norms in favour of testing children for HIV and ensuring that children and women found to be living with HIV are enrolled and retained in care. This way the programme is improving the ability of community members to access health information and other services and also supporting communities to identify, express, and resolve their own problems. The programme has found that, to ensure that the process of health education is uniform, it is important for community interventions to produce standardised messages for use during community dialogue and health education sessions.

By linking community, health facility and district level actors, the programme provides opportunities for advocacy and feedback, as well as civil society participation in the oversight and monitoring of the health system. Identified gaps in eMTCT and paediatric HIV care such as stock out of HIV test kits

and ARVs had been addressed by working with PLHIV and relevant District Health Teams and national level actors. The problem was solved in some of the health facilities, by transporting supplies from health facilities which had a surplus, to those with shortages. Another gap identified through health facility dialogue meetings relates to the limited number of health workers which affects the quality of services provided. This gap has not been addressed due to budgetary limitations. Another key advocacy issue identified was the need to meet the nutritional needs of women and children living with HIV, which programme implementing partners addressed by linking up with organisations working on nutrition. The lack of a clear strategy for channeling advocacy issues generated through the programme to national level policymakers is a challenge that requires attention.

# 2. Community networks, linkages, partnerships and coordination

- Build networks and linkages of CHWs and other CoRPs
- Map out and link key CoRPs, community groups and organisations relevant to paediatric HIV prevention and care
- Bring different actors together to strengthen tracing, referral and follow-up support for children living with HIV

**TAFU programme experience**

The programme is building networks of CHWs, other CoRPs and community groups, such as PLHIV networks in a coordinated manner to better serve their communities. Key CoRPs, community groups and organisations relevant to addressing the health and socio-economic needs of women and children living with and affected by HIV in project areas have been mapped. This includes paediatric HIV prevention and care; target populations; and resources available and needed to perform the expected roles. Guided by the identified capacity needs of these community systems, these community actors are being trained by programme partners in collaboration with District Health Teams and HIV implementing partners thus leveraging available resources and avoiding duplication of services. In addition, collaboration amongst community system actors enables more effective service delivery and advocacy, and greater impact.

During the early years it became apparent that the programme needed to establish linkages with other departments at district level beyond the health sector. This is likely to further improve the effectiveness of community and health facility support interventions for women and children.

**"Incorporating 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

# 3. Resources and capacity building

- Train CHWs and other CoRPs in paediatric HIV care and support
- Tap existing resources for building capacity of CHWs, CoRPs, and health facility staff
- Facilitate acquisition and distribution of updated guidelines and information resources on eMTCT and Paediatric HIV care
- Provide CHWs and CoRPs with means of transport and reference materials to reach out, engage, educate and support communities
- Train and supplement VSLA's efforts to meet the financial needs of women and children
- Pay salaries of staff directly involved in programme implementation
- Share expertise and tools among programme partners

**TAFU programme experience**

TAFU partners work to improve access to human and material resources for health by developing the capacity of community and health facility actors. This is achieved primarily through identification, training and mentoring of CHWs, other CoRPs and HCWs. All are trained in eMTCT and paediatric HIV, which equips them with the right knowledge, skills and attitudes to ensure that all children living with HIV are identified, linked to services and retained in care. Training events are conducted in partnership with District Health Teams and major HIV implementing partners. Using existing District Teams has made follow-up and further support of trainees more cost effective and sustainable. In addition, partnerships with the Ministry of Health, District Health Teams and other HIV implementing partners within the TAFU districts has facilitated the distribution of updated guidelines and information resources - especially on eMTCT. CHWs and CoRPs are given travel expenses or bicycles to enable community outreach, engagement, education and support, especially to women and children living with HIV. A small amount of top-up funding is also provided to supplement VSLA efforts to meet the financial needs of women and children targeted by the programme.

Within TAFU partner organisations, the programme covers salaries of staff directly involved in project implementation and also covers administrative costs. Quarterly partner review meetings provide valuable opportunities for mutual sharing and learning. In this way and numerous others, partners share their expertise and tools with each other.

**"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..."**
– Focus Group Discussion caregivers, Bulela Health Centre, Mityana).

It is important that capacity building efforts for CSS build on national and district level efforts and include use of existing guidelines, training manuals, district and implementing partners in training and mentoring HCWs and CoRPs. In addition, programme designers and implementers should avoid working with blueprints, and constantly adapt CSS interventions to the context.

## Community System Strengthening through strong partnership

The TAFU programme increases partners' capacity to address eMTCT and Paediatric HIV care by drawing on existing capabilities among implementing partners.

- ✓ **The National Forum of People Living with HIV/AIDS Networks in Uganda** provides technical support in training and building the capacity of support groups for women and children living with HIV in all TAFU districts.
- ✓ **Community Health Alliance Uganda** helps partners strengthen their monitoring systems and access required guidelines - especially from the Ministry of Health.
- ✓ **Health Need Uganda** shares its experience and early insights gained from working with village health groups which are piloting a community health insurance scheme for maternal and child health, and engaging schools in paediatric HIV prevention and care.

# 4. Community activities and service delivery

- Work with CHWs and other CoRPs to conduct outreach, home visits, health education so that they can identify, refer, and follow-up women/children living with HIV
- Address stigma as barrier to women/children's enrollment and retention in HIV care
- Work with VSLAs to address financial needs of women/children living with HIV
- Link with schools/teachers for community mobilisation and support

**TAFU programme experience**
The TAFU programme seeks to increase the quality of HIV/AIDS services and ensure that service delivery mechanisms and services themselves are aligned to the needs of women and children living with HIV or exposed to it. Key activities include training health care providers, reducing stigma and discrimination and improving stock management. The programme engages with CHWs, who do outreach, health education, make referrals and follow-up on health needs. They are trained and supported to reach families that are not yet enrolled in eMTCT and paediatric HIV care; to address knowledge gaps on paediatric HIV; and to reduce stigma at household and community levels. In the first years of the TAFU programme it became clear that there are additional resource people in communities – known as Community Resource Persons (CoRPs) – who can also reach out to families and communities. These include expert clients, mentor mothers, religious and local leaders.

The CHWs are attached to health facilities to supervise, feedback, report and engage in activities such as distribution of drugs, health education and drug adherence counselling. Because they work both in communities and health facilities, CHWs can trace clients who have not been followed-up and facilitate their re-engagement to care. They are therefore the perfect connection between communities and health care facilities.

**"At first, I feared a lot when I was told I have HIV. But when I attended a meeting I realized I am not alone, I gained the courage to go on, take my drugs and I gave birth to an HIV negative baby ..."**
– Focus Group Discussion Mothers eMTCT, Ntungamo

**"When you meet other children living with HIV you realise you are not alone and get courage to continue taking your drugs to stay alive...Sometimes you feel down but when we attend the meeting and participate in music and sports, when you go back you are feeling better ...."**
– Focus Group Discussion Children Living with HIV, Ntungamo

The main lessons have been the need to link with schools (see Box) and the need for standardised information materials to guide CHWs in their community mobilisation and education efforts.

## TAFU outreach to schools

During the first years of the TAFU programme, schools and teachers emerged as key actors to assist in reaching out to children living with HIV and their caregivers. As a result, the programme now works with primary school teachers, school management and children support groups primarily to reduce stigma in the schools and thus create an enabling environment and support for the children living with HIV to adhere to their treatment. In addition, schools are now used as an entry point to identify other children living with HIV who have not yet been traced. They are then encouraged by the teachers to talk to their parents and go for testing. Thus support groups working with schools reduces stigma in both schools and the community and increases the number of children identified living with HIV.

# 5. Organisational and leadership strengthening

- Conduct quarterly programme partner review and exchange meetings.
- Share tools, guidelines, training manuals and expertise among programme partners.
- Coordinate effectively between CHWs, CoRPs and health facilities.

**TAFU programme experience**

Recognising the importance of effective and sustainable governance of health and community systems, the TAFU programme strives to build the capacity of partner organisations through quarterly review and exchange meetings. These are hosted by different partners to facilitate on site learning. In addition, tools, guidelines on topics such as report writing, data collection, training/mentoring CoRPs and best practice are shared regularly among partners.

Advocacy concerns raised by communities are often shared during meetings. This promotes a "watchdog" role in monitoring health-related policies and programmes. It also increases awareness within local and central government regarding the needs of communities they serve. One of the issues that has been raised from local to district level is the need to address regular stock-outs of HIV test kits and drugs.

**"Before TAFU came, there were no support groups or meetings for children living with HIV. With TAFU support we started holding meetings for these children to discuss the challenges 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 in caregiver meetings..."**

– Health Worker, Kiganda Health Centre, Mubende

# 6. Monitoring, evaluation and planning

- Conduct baseline and end line assessments and develop monitoring and evaluation framework.
- Disseminate results from baseline and end line assessments at district and national levels.
- Adapt existing data collection tools and develop tools for specific programme indicators.
- Train CHWs, CoRPs and health care workers in data collection.

**TAFU programme experience**
The programme has conducted baseline assessments and developed a monitoring and evaluation framework. In addition, an end line assessment for Phase 1 was conducted in 2017 and its lessons have informed further programme interventions. Findings from all assessments have been shared with national stakeholders and internationally with relevant policy makers, researchers and donors.

Increasing community and health system capacity for collecting, analysing, and responding to health-related data is critical to ensuring that health policies and service delivery mechanisms meet the needs of the populations which the health systems serve, and that communities are able to identify and resolve their own health challenges. Data collection tools have been adapted from existing health information system tools and some tools developed for specific project indicators. CoRPs and HCWs have been trained on use of data collection tools. It is critical that this training goes beyond data collection to include analysis, reporting, dissemination and use of data to inform service improvements and replication.

**"When TAFU had first come, we had 20 – 30 children in care. When the programme trained and used CHWs, today we have between 50 – 70 children in care at the health centre."**
– Health Worker, Bulera Health Centre , Mityana District

# 4. Scale up and replication of the TAFU community intervention model for reaching all children exposed to HIV

To reach ALL children living with and/or affected by HIV, the gap between health facilities where much of the care is provided, and the communities, where children are conceived, born and cared for, needs to be bridged.

### TAFU Key Results

During the TAFU programme the community intervention model was successfully implemented and further developed. The programme has increased awareness on paediatric HIV, trained community actors to identify, refer and follow-up on children and women exposed to HIV, reduced stigma and facilitated socio-economic empowerment of HIV affected households. Some of the key results from the first two years of programme implementation are summarised in Table 3.

### Key success factors

One of the key success factors leading to the results described above is the holistic approach of the programme. By bringing a diverse range of stakeholders together at district level the programme has addressed multiple barriers (such as stigma and poverty) and at the same time built on existing community systems and district health systems. Ensuring that CHWs are capable of acting as the linking pin between communities and health facilities has been key to effectively completing the trace-referral-enrollment-follow-up loop. Training and continuous support of CoRPS has been critical to success, backed up by the provision of quality reference materials with visual aids, in appropriate languages.

## Table 3: achievements TAFU programme first 2 years (2015-2017)

| | Indicator | No Reached |
|---|---|---|
| Training | Community Health Workers trained on Paediatric HIV | 327 |
| | Community Resource Persons trained on Paediatric HIV | 1,051 |
| Outreach | Household visits by Community Resource Persons | 3,839 |
| | People reached through community dialogue meetings | 9,808 |
| | People reached through health facility information sessions | 7,338 |
| Support Groups | Children / Adolescent peer support groups formed | 16 |
| | Children supported through peer support groups | 859 |
| Children | Children tested for HIV | 5,051 |
| | Children in care in target areas at baseline in 2015 | 459 |
| | Children in care in target areas at end-line in 2017 | 1,017 |
| Women | Women enrolled in eMTCT / HIV care | 1,355 |
| | Women and caregivers of children supported in VSLA groups | 1,008 |

**"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..."**

– Person Living with HIV, Mityana district

**Lessons learnt :**

- ✓ Building bridges between CoRPs and health facilities is feasible and improves the identification of children and women exposed to HIV, leading to better linking into care and retention.
- ✓ Use of expert clients is a preferred way to reach PLHIV including children; they are able to draw on their experiences to empower other women and children especially those who have recently tested HIV positive.
- ✓ VSLAs offer economic empowerment to HIV affected families and an additional space to address the needs of children living with HIV and their families.
- ✓ Community systems, if empowered, can help raise the red flag on crucial issues that need to be addressed by the health system, such as drug stock outs and stigma in health facilities.
- ✓ It remains important for global and national actors in HIV prevention and care to ensure that interventions do not become thwarted by stock outs, inadequately skilled health workers, continued stigma, and insecure livelihoods.

## Recommendations

Based on the positive results and valuable lessons learnt from the TAFU programme to date, there is an opportunity to achieve significant improvements for children who are exposed to HIV, by linking them to the specialist care and support they need. Aidsfonds and its partners propose a roll out of this successful community intervention model, both in Uganda and in other countries. In 2018 Aidsfonds and its partners began implementing the model in Zimbabwe and Kenya. To achieve further scale up, we would recommend the following actions:

**National government(s) to:**

- ✓ Facilitate implementation of the community intervention model throughout the health system, by
  - creating enabling policies and laws,
  - providing adequate financial and human resources to support the adoption of the approach and
  - addressing crucial health system barriers such as stock-outs, capacity gaps of health staff and payment of Community Health Workers;
- ✓ Work with local communities to adapt the model to reflect local needs and priorities;
- ✓ Work with the Ugandan government as a champion of the approach.

**NGOs, CBOs and other health implementing partners to:**

- ✓ Analyse their own intervention models based on the six pillars of the CSS framework;
- ✓ Implement an adapted community intervention model based on the TAFU experience in their own geographical area;
- ✓ Share learning experiences with the TAFU programme team to further enrich the model and its potential for wider uptake (eg how did the model help further your goals towards reducing MTCT/paediatric HIV, what difficulties did you encounter with the model?);
- ✓ Engage with Aidsfonds to explore potential for collaboration around extending community involvement in programmes.

**Donor agencies to:**

- ✓ Engage directly with NGOs and CBOs implementing evidence-based community intervention models using the TAFU experience;
- ✓ Support and champion the community intervention model as an essential methodology to: find and treat all children living with HIV; complement the health system approach for children and achieve the global AIDS goals;
- ✓ Identify ways in which the evidence-based community intervention model could be integrated as a key component of the grant process (eg all grant applicants to show that they are integrating a community intervention led approach);
- ✓ Analyse their current funding portfolio to see to what extent they support the six pillars of the CSS framework.

**"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

# Endnotes


1 Global Fund to fight AIDS, Tuberculosis and Malaria (2014). Community Systems Strengthening Framework.

2 The Republic of Uganda (2015). HIV and AIDS Uganda Country Progress Report 2014. Kampala: Uganda AIDS Commission

3 Ministry of Health (2017), Preliminary Results of the 2016 Uganda Population HIV Impact Assessment: Kampala.

4 UNAIDS (2016), Global AIDS update 2016: Geneva.

5 Rujumba J, Ahumuza S. & Tushabe A. (2017). Towards an AIDS Free Generation in Uganda Program: Endline Survey Conducted in Serere, Moroto, Napak, Mubende and Mityana Districts, Kampala: Aidsfonds and partners in Uganda.

6 Start free, stay free, AIDS free: A super-fast-track framework for ending aids in children, Adolescents and young women by 2020 (UNAIDS and partners)

7 Full name of the programme is now: Towards an AIDS Free Generation in Uganda: communities taking lead in reaching all children!

8 In Uganda these are Village Health Teams

9 The Joint United Nations Programme on HIV/AIDS (UNAIDS), the World Health Organization (WHO); the United Nations Children's Fund (UNICEF); the World Bank; MEASURE Evaluation; the Coalition of the Asia Pacific Regional Networks on HIV/AIDS (7 Sisters); the International HIV/AIDS Alliance; the United States Agency for International Development (USAID) Office of HIV/AIDS; the U.S. Office of the Global AIDS Coordinator (OGAC); United Nations Development Programme (UNDP) Burkina Faso; Ministry of Health and Social Welfare Tanzania; independent consultants and Global Fund staff).

Rujumba J, & Tushabe A. (2015). Towards an AIDS Free Generation in Uganda (TAFU) Program: A Baseline Survey Conducted in Serere, Moroto, Napak, Mubende and Mityana Districts. Kampala: STOP AIDS NOW!, ICCO Cooperation and Partners in Uganda.

Rujumba J, Ahumuza S. & Tushabe A. (2018). Towards an AIDS Free Generation in Uganda (TAFU 2) Program: communities taking lead in reaching all children! (TAFU2). A Baseline Survey Conducted in Soroti, Ntungamo, Mityana, Mubende and Kyenjojo Districts, Kampala: Aidsfonds and Partners in Uganda.

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