Towards an AIDS free generation

# Communities taking lead in reaching all children living with HIV

## Towards an AIDS free generation program in Uganda (TAFU2)

Mid term report, November 2018

aidsfonds

# Introduction to TAFU

**The four-year Aidsfonds-initiated Towards an AIDS Free Generation (TAFU) programme aims to reduce the number of new HIV infections among infants and increase the number of children living with HIV (0-14 years) on treatment. In 8 districts in Uganda we test and further develop our community intervention model.**


Towards an AIDS free generation (TAFU) is a community based programme. We address social and economic barriers, including stigma and poverty, that are hindering children living with HIV access to treatment, by:

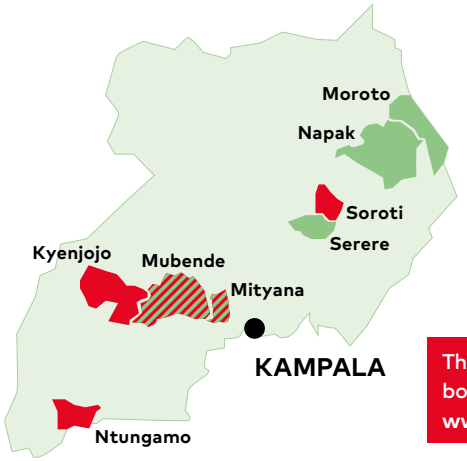
- ✓ capacitating community groups to take lead in reaching all children;
- ✓ strengthening collaboration between community structures and health facilities, towards a more effective tracing, referral and follow-up system for children affected by HIV;
- ✓ using and building on national and district level strategies, policy guidelines and service delivery systems.

# The context

Despite steady progress in addressing paediatric HIV in Uganda, 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. 95,000 children aged 0-14 are estimated to be living with HIV[1]; 62 percent is on antiretroviral treatment (ART)[2].

To reach ALL children living with or affected by HIV, we need to bridge the gap between health facilities where much of the care is provided, and the communities, where children are born and cared for.

The TAFU programme started in 2015 in 5 districts in Uganda: Napak, Moroto, Serere, Mityana and Mubende. In 2017 we were able to scale up the successful approach of the programme and expanded to 3 new districts: Soroti, Kyenjojo and Ntungamo. In Mityana and Mubende we continued the programme. TAFU2 runs up to mid 2019.




The TAFU community intervention model booklet is available for download on **www.aidsfonds.org/tafu-model**

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

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

**"Sometimes I fail to take my granddaughter to the facility when her appointment is due and she ends up going for some days without medication until I get the money"**
– Said a grandmother in Mityana

# Midterm Results

**Mobilise and educate communities on paediatric HIV and eMTCT**

- ✓ 243 Community Health Workers (CHWs), 119 other Community Resource Persons (CoRPs) were trained in paediatric HIV care and support and eMTCT, in creating linkages to enable complete trace-referral-enrollment-follow-up loop and in data recording and documentation.
- ✓ 4808 household visits were done 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.
- ✓ 335 community dialogues facilitated by CHWs and health care workers, carried out at community level to create awareness and reduce stigma among community members in order to support families to access paediatric HIV services and retain in care.

**HIV Testing**

- ✓ CHWs helped mobilise and refer pregnant women and children to health facilities for HIV testing as well as mobilise for community based testing during outreaches.
- ✓ CHWs carried out household visits and through these they were able to identify children whose HIV status was not known when in some cases the parents knew their positive status. These children were referred for testing and some of them have been found to be HIV positive and enrolled into care.

**Enrollment in care**

- ✓ Reports from health facilities indicate that there has been an increase in the number of cases enrolled into care, both new and those that had dropped out of care and this has been from the referrals made by the CHWs.
- ✓ The CHWs also participate in health facility sessions especially during ART days and information regarding paediatric HIV is shared.
- ✓ In order to strengthen support for children in schools, 147 teachers were trained in paediatric HIV and how to support these children. The trained teachers have carried out 100 school sessions together with CHWs and this has helped parents to come out and allow the testing of their children.

**ART initiation**

- ✓ Production and distribution of training manual for CHWs/ CoRPs, information leaflets, TAFU-calendar
- ✓ Lobby for better supply management of drugs and testing kits.

**Retention in care**

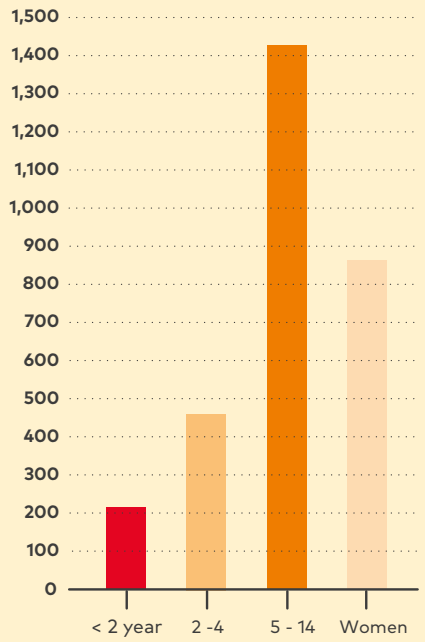
- ✓ We started 38 peer support groups for children caretakers; in these groups the children and their caretakers can share experiences and barriers and help each other in treatment adherence.
- ✓ 41 Village Saving and Loans Associations (VSLAs) were started to help caregivers meet nutritional, health care and other needs of children; 895 VSLA members were trained
- ✓ The teachers are also helping in drug adherence by reducing stigma in schools.

**Cross-cutting: stigma reduction**

- ✓ Many of the activities that were done contributed to reducing stigma: the training of CHWs/CoRPs, the household visits, the community dialogue meetings, the peer support groups, the VSLAs, strengthening the capacity of CHWs.

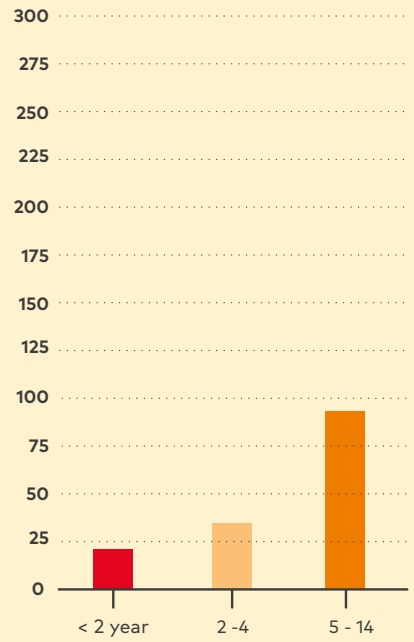
## Children and women tested for HIV

Total target is 4,000




## Children enrolled on ART

Total target is 3,600




**"Missed appointments have been reduced due to improved coordination between the health workers and the CHWs and CoRPs. This has made follow up easy"**

– Fred Akugizibwe, health facility Kyenjojo district

# Lessons learnt

✓ In the program we have spent quite a lot of time in strengthening and building the community structures, before we could actually start referring children and retaining them in care. **The CHWs and CoRPs needed to be trained, and district and health facility staff needed to be brought on board.**

✓ **Then the CHWs/CoRPs needed to identify the households which have children 0-14, women in reproductive age, pregnant women.** This then enables us to focus on these households in our activities: household visits, community dialogues.

✓ **This whole process of building structures and identifying households has taken some time, but is necessary to be able to work in a focussed and effective way.** We are expecting that in the remaining program period the results and outcomes will accelerate.

✓ **The VSLA groups facilitate economic strenghtening of the caretakers and at the same time are a good vehicle for information sharing on e.g. HIV and nutrition, and can act also as support system for treatment adherence.**

✓ **We asked ourselves the question: are the right children/adolescents tested? If we only test the children of people who are on ART, we are missing out a large group.** Those whose parents are ignorant of their own HIV status or haven't disclosed their status. But also the adolescents who have sex or are abused are often missed out, because parents are in denial and/or health workers ask the wrong questions to the wrong people.

✓ **Stigma is still hindering children accessing treatment; stigma in the household, in the schools, in the community, in the health facilities.** We are addressing this through household visits, community dialogues, support groups, information sessions at health facilities and in schools.

✓ **Psychosocial needs of children need to be dealt with; and there is a need for parenting support,** e.g. to support parents in disclosing the HIV-status to their children.

✓ **The alignment with other actors at district level is crucial in reaching our goals and requires some kind of facilitation/support.**

✓ **Sustainability of the community model, with the CHWs/CoRPs having a central role, is important.** Therefore we are now looking into ways to sustain their roles, to make them economically independent. We are trying out a VSLA for the community workers themselves.

## Next steps

In the last year of the TAFU program we will be focussing on achieving our ultimate target: enrolling 3600 children living with HIV on treatment. To achieve this we will accelerate our activities and adjust our approach to address the barriers we are facing in reaching the children, such as community outreaches for testing.

In addition to creating impact in Uganda, Aidsfonds is constantly improving the intervention model with experiences from Uganda and other countries. Aidsfonds is currently expanding its paediatric HIV model to Zimbabwe (June 2018), Kenya (end 2018) and Mozambique, Nigeria and South Africa (early 2019). The main objective in scaling is to improve impact (more children found and linked to care & support) and to showcase a standardized way of working in community interventions related to paediatric HIV. Aidsfonds will create a linking and learning initiative to align work in these six countries and to further shape the intervention model. This will be done in collaboration with Elma Foundation and ViiV Positive Action for Children Fund/ PATA.

Towards an AIDS free generation

**TAFU implementing partners:**

NAFOPHANU

Community Health Alliance Uganda

Arise

HEALTH NEED UGANDA
Education, Health, livelihood

## A referral from the community health worker saved Bright's life

**Six-year-old Bright from Mubende experienced severe malaria and developed a skin rush all over his body. His father could only buy simple tablets like pain killers and anti-malaria from the drug shop to treat malaria. In January 2018, during his household visits community health worker Kyarimpa Francis identified Pascal's home and encouraged him to take all his children for HIV testing.**

**My responsibility**
"I was in shock that Bright and I were HIV positive. But I was grateful that two of my children were HIV negative," the father narrates. Health worker Francis: "I felt it was my responsibility to follow them up and make sure they were enrolled into care. I also continued counseling Pascal since he is a widower and has to live and take care of his children."

**Empowered**
Pascal: "We now take our ARVs very well as directed by Francis - every day at 8:00PM after eating. Bright has gained appetite for food, he no longer gets fever. I really thank Francis for saving our lives." During a community dialogue meeting, Pascal shared his personal testimony. He encouraged his fellow men to take on their responsibilities as family heads and take their children for HIV testing.

**Work with different partners**
Francis: "I follow up my clients to ensure that the referrals are complete. I work with other implementing partners like the children's development centre and clinics within my sub-county. During the paediatric HIV care and treatment workshop that was facilitated by Community Health Alliance Uganda we learned to work with different partners. I want to thank TAFU project and CHAU for coming to our sub-county. HIV positive people have been identified and enrolled into care."