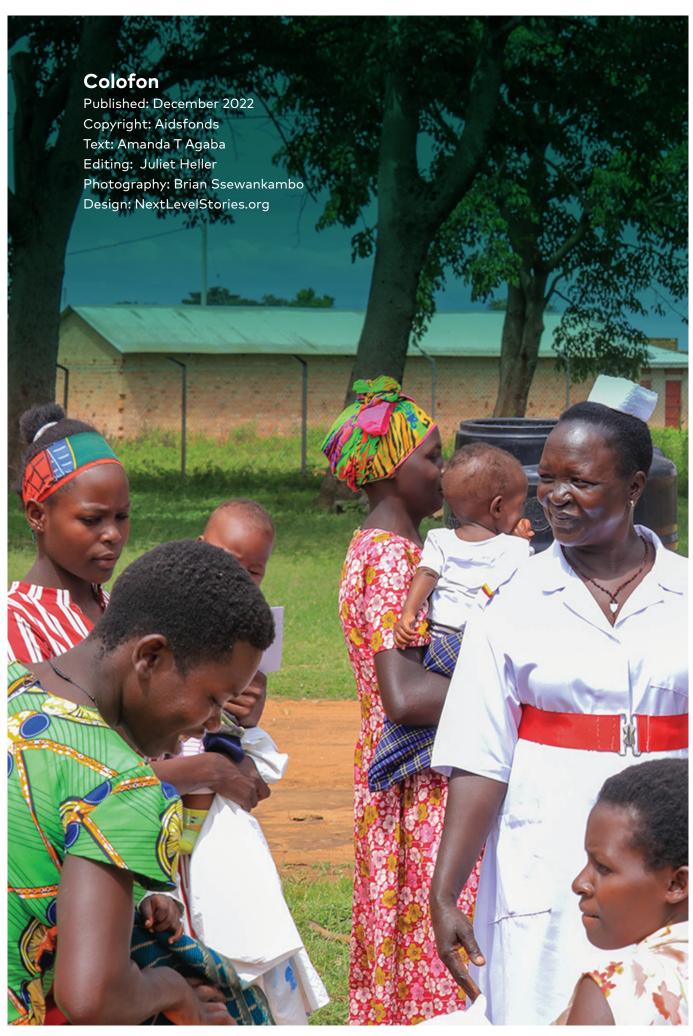
Community Breakthroughs

# Community-led Interventions for an AIDS-Free Generation

Stories from Uganda





It truly takes the village, the community to raise children. Communities are where children are born, live, and pursue their dreams. Any initiative to reach children must then start with the heartbeat of the community - its greatest resource, its members.

Welcome to an inspiring collection of voices, on community led interventions supported by Aidsfonds and its partners aimed at ending paediatric HIV in some of the worst affected areas in Uganda.

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### Words to know

ARI	Antiretroviral treatment
HIV	Human Immunodeficiency Virus
PMTCT	Prevention of mother to child transmission
TAFU	Towards an AIDS Free Generation in Uganda
VSLA	Village Saving and Loans Association

### **COMMUNITIES FIRST**

### The Kids to Care community intervention model

Investing in communities is investing in a healthy future generation. Strengthening the capacity of communities ensures that households are linked to care, support and resources to enable them to thrive as well as to advocate for better services.

For years, Aidsfonds has collaborated with communities, governments, civil society, faith, and culture leaders and other funders in Uganda to address deep-rooted challenges facing the HIV response. Aidsfonds works in partnership with governments and in-country partners, to test and scale up community-based HIV programmes. These are based on the 'Kids to Care model' community intervention model that is part of our Paediatric HIV approach to ensure children can live healthily with HIV. This model empowers communities to find and support children and pregnant women living with HIV and strengthens the links between communities and health facilities. Community health workers play a central role in this model and are a crucial link at all four stages of HIV care for children: finding those with HIV, ensuring they are tested, are started on treatment and supported to stay on it.



#### THE CHANGE MAKERS

In this document we share some of the faces and voices from communities in Soroti and Mubende districts in Uganda including community actors working to bridge the gaps and break the barriers to reach all children living with or affected by HIV. These community actors include health workers, community health workers, peer support group members, members of social economic empowerment groups, mentor mothers, and youth adolescent peer supporters. The achievements they share are to a great extent the result of using the Kids to Care community model supported by Aidsfonds and partners under the Towards an AIDS Free Generation in Uganda programme<sup>2</sup> and the Paediatric HIV Breakthrough Partnership<sup>3</sup>. In Soroti, Aidsfonds partners with Health Need Uganda and in Mubende with Community Health Alliance Uganda. Aidsfonds also works with the National Forum of People Living with HIV and AIDS in Uganda (NAFOPHANU) in both districts.

Every community actor's contribution is critical; working together they support families to attain and sustain good health and wellbeing.



Health workers, midwives, nurses and clinicians at health facilities provide HIV prevention including preventing mother to child transmission (PMTCT), counselling, testing, treatment for paediatric HIV and work with community health workers to ensure no children or families miss out on quality care.



Village Savings Loans and Associations (VSLA) help caregivers, community health workers and resource persons meet nutritional, health care and other needs of children and empower members to improve their livelihoods and household incomes.



Community health workers and other community resource persons play a vital role in collaborating with health facilities to create effective linkages that enable a complete trace-referral-enrolment-follow-up loop of exposed women and children. During household visits the community health workers also educate people on paediatric HIV care and support, follow up on HIV care and link households to other community support systems.



District departments, local government representatives/leaders and decision makers who through the advocacy of communities work to prioritise quality paediatric HIV services.



Peer support groups for children and their caregivers, youth and adolescents provide safe spaces where they can share experiences and barriers and can help each other in treatment adherence.



Civil society, implementing partners advocate and align activities with other relevant health partners to improve the quantity and quality of service delivery at both health facility and community levels with the support of funding from the Breakthrough Project.

<sup>2</sup> www.aidsfonds.org/tafu

<sup>3</sup> www.aidsfonds.org/breakthrough

### **IN NUMBERS**

### Selected achievements by Aidsfonds partners Health Need Uganda and Community Health Alliance Uganda:



### 2015-2022

416

community health workers trained to identify, refer and follow-up on children and women exposed to HIV, reduced stigma and facilitated socio-economic empowerment of HIV affected households 33,004

women referred to antenatal care

24,548

children and mothers tested together

911

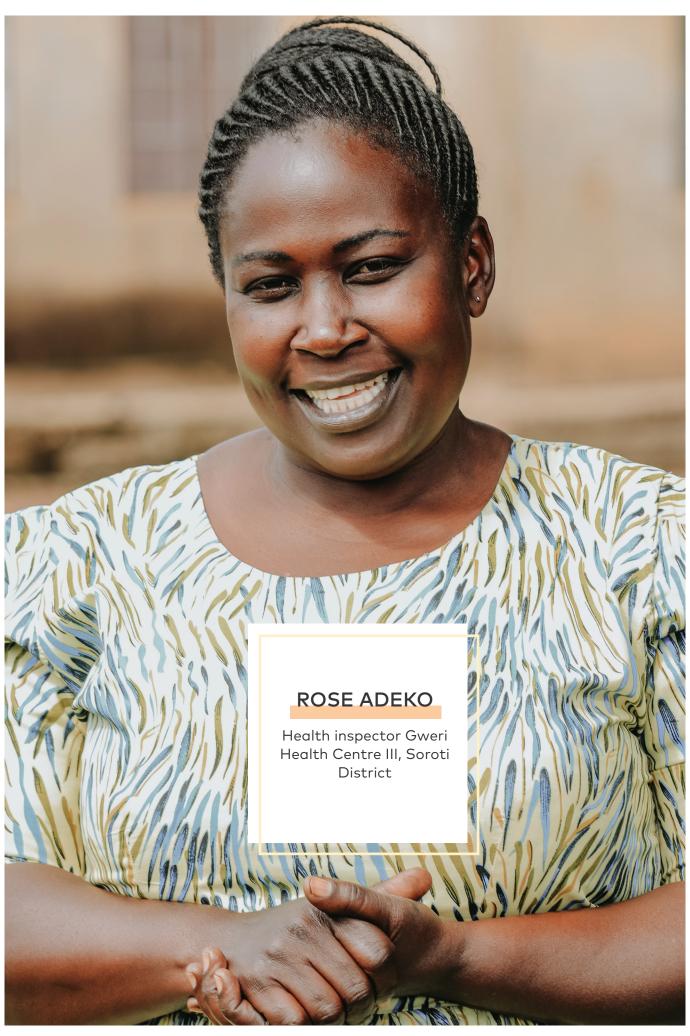
children and mothers linked to HIV treatment services

175

children born since 2020 to HIV positive mothers (supported by project) but are HIV negative



Local government leaders reflect on the past and share how strengthening community systems is changing the future of the paediatric HIV response.



#### BRIDGING THE GAP

"In the past, parents hid their children's HIV status at all costs", says health inspector Rose Adeko. "Sometimes parents shared their medication with their children at home hoping it would work. They feared that if the children came to the health centre for treatment people would see them, the gossip would start and soon they would be excluded from activities with other children in the community".

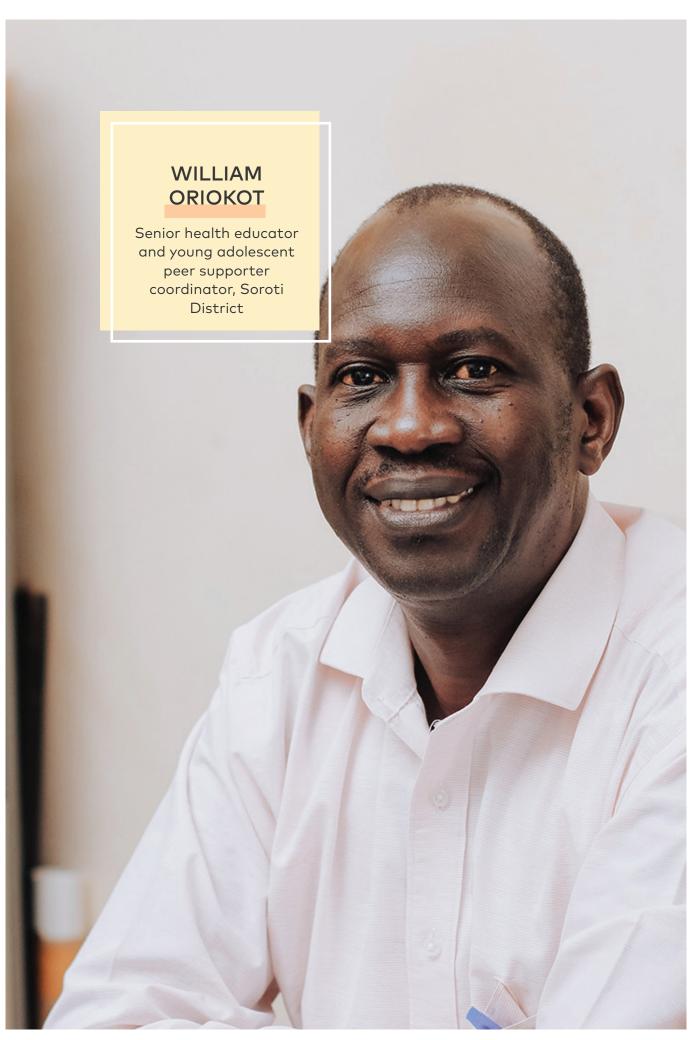
Rose also believes that even when parents knew they had HIV some hoped that the children would survive it - in many instances it was a form of denial that put many infants' lives at risk.

Rose emphasises that health care workers have done their best to educate parents enrolled in care on the importance of treating children exposed to HIV but it was not enough. She admits that there was also a gap between schools and hospitals. It was important for health care workers and teachers to support families affected by HIV together and promote the same message.

When the Kids to Care community intervention model was expanded to include raising awareness at schools, things started to change. Rose was delighted, because one of the areas where children were most stigmatised was at school.

"Teachers were trained on HIV prevention and lifesaving medication, which if taken properly would give children living with HIV an opportunity to live successful lives. The teachers were taught how to handle disclosure, create safe spaces for children to take their medication, offer school-based counselling to support children living with HIV and promote an inclusive school environment".

The good news - like all news in small communities - spread fast: more parents gained courage and started bringing their children to the health facility. But the community intervention team also brought the teachers and health care workers together to look out for children and families in their care and ensure that none were missing medication, taking action if anything was changing with regard to theirs or their family's wellbeing.



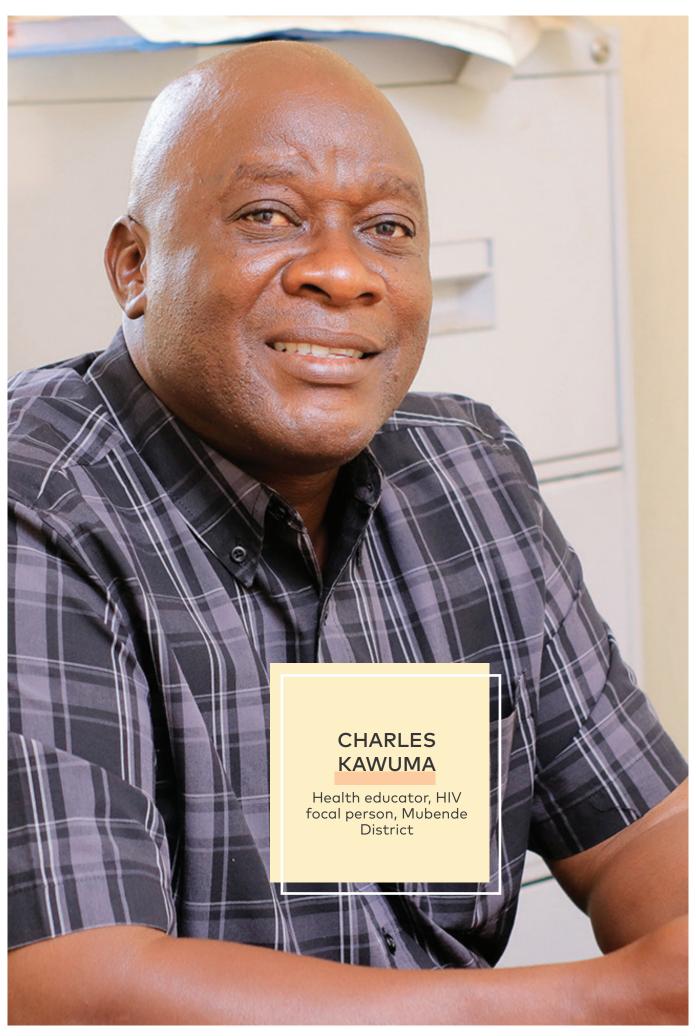
### TRACING 'LOST' CHILDREN

"This community intervention model has been instrumental in one of the most critical areas of HIV and AIDS-paediatric HIV, preventing it, and treating exposed infants and their mothers at the community level. The intervention helped raise awareness on the importance of preventing and addressing HIV. Viral suppression was a big challenge in our area, mothers would disappear, yet children have no way of getting themselves to treatment. This also enabled community health workers to reach out to households and we have seen several children and caregivers who we had considered lost to follow up, now successfully back in care".

William is also pleased that the community intervention model is holistic in addressing the realities of people living with HIV in low income settings.

"The triple mix porridge, rich in nutrients and made from locally available foods including millet, soya, and groundnuts, has helped boost families' nutrition and as such improved treatment outcomes. Additionally, helping establish Village Saving and Loans Associations will go far in enabling the community including community health workers themselves to sustain their livelihoods. Previously, community health workers would find it hard to support others when their own families were struggling to have their basic needs met. The community intervention has also promoted local ownership in every area. It has brought together various actors already established here including other HIV/AIDS focused non-governmental organisations such as The AIDS Support Organisation (TASO), Mildmay, and other partners committed to ending childhood HIV."

"The community intervention has also promoted local ownership in every area"



## COUNTING THE MOST IMPORTANT WINS FIRST

Charles Kawuma recognises how impactful the community led approach has been on rallying both the community and health care workers around addressing paediatric HIV. Charles highlights that youth voices and mothers living with HIV have been elevated and the gaps in care between community and health centres reduced.

"The youth voices in HIV are now more noticeable. It has helped us know the issues faced by the youth and what to address. For example, we no longer work through generalised services and use more youth-friendly services. Using the youth peer educators supported by PATA (a Breakthrough project partner) has helped us with awareness raising to reach more young people than ever before. We have realised a closer connection between our health centres and the communities which has improved client tracing, referral and ultimately treatment outcomes. Much as we persistently have few health workers, these trained youths and community structures help with mobilisation and basic health education to reach fellow young people and other targeted groups such as mothers, caretakers, and exposed infants".

He recognises that using multiple pathways in the community, at the health centre, and ensuring that the various community workers are well trained and linked together is crucial for paediatric HIV prevention and care.

"Moving forward, we are sure we can sustain a number of efforts started because of the technical capacity built within our health officers. I have observed a culture of ownership built within our community health workers, the youths, and health officers which will keep the changes alive."

"I have observed a culture of ownership built within our community health workers, the youths, and health officers"

## IMPROVING HEALTH CARE-Service Providers



Midwives, nurses and clinicians at health centres let us into their lived experiences in the response to prevent new HIV infections, and support children and families living with or affected by HIV.



### ON MIDWIVES AND BIRTH JOURNEYS

Rosemary and the other midwives in this area were excited that more women were being referred by community health workers for antenatal services. The midwives were delighted to give pregnant mothers what are known as 'mama kits' a month before birth. These are birthing kits comprising materials used during newborn delivery. For families in underserved areas that cannot afford to pay for birthing supplies mama kits are an excellent gift. The midwives hoped the kits would motivate mothers to return to the health facility and have their babies there. But surprisingly, mothers were not returning, and instead choosing to give birth in their homes with the help of older women or with traditional birth attendants. For mothers living with HIV, this puts their babies at greater risk of exposure. The community intervention model's emphasis on closing the gaps in the childbirth journey led to the focus on building and strengthening networks of mentor mothers to accompany expectant mothers living with HIV, encourage and support them to attend all their antenatal clinic days, take their medication, help address their fears and prepare them for a successful birthing experience at the health facility. The mentor mothers work closely with the community health workers in the community and with health workers to ensure mothers have the right information to enable a healthy pregnancy, delivery, and appropriate newborn and child care. Midwife Rosemary is glad to report on the improvements.

"At Gweri Health Centre III the health workers make a list of mothers and children who have missed the appointment and give it to the community health workers and the mentor mothers who conduct community follow-ups to find out why they didn't come. They talk with families, counsel and support them to get back on track. We have also changed the time of providing mama kits and give them at labour and delivery. Facility births have increased from 30 to 70 per month and we are now considered a model facility because of how we track and support mothers through the mentor mothers and community health workers. We are now supporting the Asuret Sub County health centre to do the same."

Facility births have increased from **30** to **70** per month



#### SPREADING THE WORD

Since 2017, Harriet has been at the forefront of the campaign towards an AIDS-free generation in her community. Harriet and the other health workers suspected that some of the reasons children were becoming HIV positive or were brought in very sick was because families and mothers in the community did not always know their status and preventive measures were not taken with most home births.

"The community intervention model changed the way we work because health workers and community health workers were supported to go to the community and provide HIV testing and counselling. When we went on community outreach, the team found many people that had never taken an HIV test in their life. Our team used a method called 'index client testing' through which we trace partners and children who may have been exposed at birth. The team linked all those they found positive to care. We found that many positive pregnant mothers had not disclosed to their partners, they were very afraid. It's not easy but we had received training at intervention start and so we talked respectfully and with care about the benefits of disclosure. Together with the community health worker and other expert clients we kept supporting those who had recently tested positive until they were able to disclose safely. Since we started going into the communities, we have increased the number of children in care more than 10 times (from two to 15)".

Even better, Harriet reports with gladness that,

"...all the mothers living with HIV in our care have delivered HIV-free babies. Our working relationship with the community health workers has grown, they are able to consult with us on any health matters or challenges when they visit families. At the facility, community health workers and other community resource persons attend learning sessions to keep abreast of current HIV prevention, treatment and care guidelines as well as family health in general".

"we have increased the number of children in care more than **10 times**"

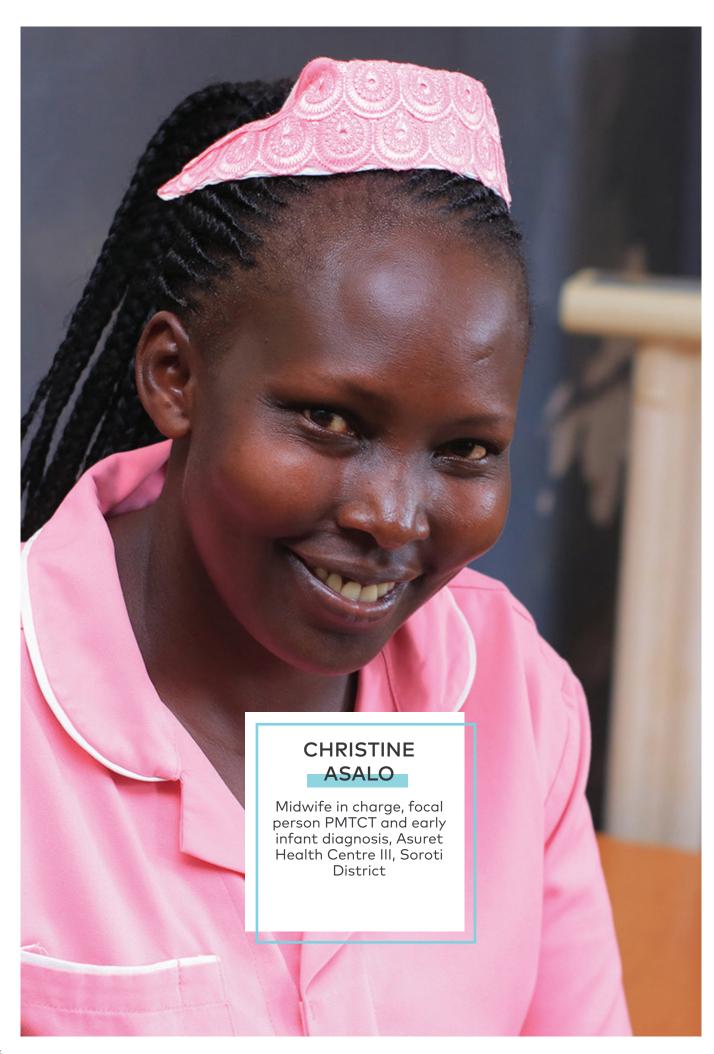


## MONEY AND OTHER CONVERSATIONS

Jennifer discovered that mothers were missing appointments but it wasn't clear why. Until as part of the community follow up, the midwife had conversations with the mothers to find out what was happening. The mothers revealed that they did not always have transport money and the distance to the clinic was too far to walk. With the support of the community intervention model the mothers formed Village Savings Loans Associations which became important sources for health loans. The mothers were also able to save funds through these groups.

"The associations then became our entry point to reach members on family health, some of them have now become family support groups through which we provide health education on topics such as adherence to medication for those living with HIV, managing nutrition for children living with HIV, Sexual Reproductive Health and Rights among other health topics. Through the VSLAs we are able to reach other women who are not our recipients of care. We would have otherwise never met these women."

"we are able to reach other women who are not our recipients of care"



#### AT THE MOTHER BABY CLINIC

Midwife Christine explains how the community systems and linkages to health facilities have been strengthened.

"I remember one of our 'lost-to-follow up mothers' who was on and off treatment since 2014. When we partnered with the community intervention in 2017, we identified a community health worker who knew the household and we worked on a new strategy to find them. Because the community health worker was from the same neighbourhood, she had heard that there were problems in the home. The reason she was not consistent with treatment was because she lived under the threat of domestic violence. If she left home to go to the health centre, she feared that her husband would assault her and scare the children. We knew that he respected some of the elders among the community resource persons, since they were already trained through the community intervention on how to address domestic violence and support people living with HIV.

We sent the older men who are by culture accorded respect, to talk with him first about how he was using his power to harm his wife, yet her desire and actions to seek treatment were the very thing that would contribute to the health of the couple. The women also counselled her and helped her to process her pain. Later the community resource persons brought the couple together, supported them to start their healing journey and referred them to the facility for medical attention. At this point the wife was on a stronger regimen - second line drugs. We came up with a treatment plan including nutrition support which the community health worker taught her about, the husband also accepted to enrol on treatment. The community resource persons continued to support them to maintain healthy living and introduced them to support groups to help them remain encouraged. There were more people looking out for the family apart from us at the health centre."

Christine lights up as she reports that the client's viral load is now suppressed, she is back on a single dose and she takes less pills, which has made it easier to adhere to treatment. Her husband is also on treatment, living healthily.

### **LIVING WELL-**

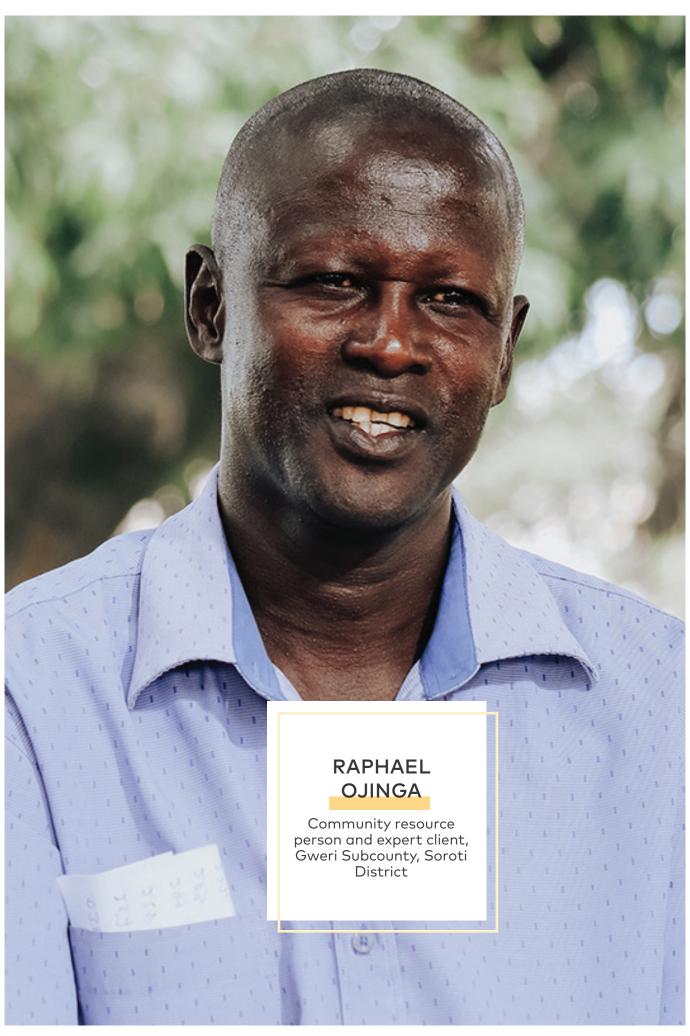
### Community resource person



Community resource persons are volunteers, well respected members of the community with sound knowledge of the culture, norms, health needs, and behaviours of their peers/neighbours.

"When we call on communities to participate to support an AIDS-free generation, we must be diligent in our empathy. Community resource persons volunteer their time, wanting the same thing - health for their people - but strapped for resources their capacity is limited. Adding a livelihood strengthening component to the community intervention model tremendously empowered them to reach more children in need of services"

- Programme officer, Community Health Alliance Uganda.



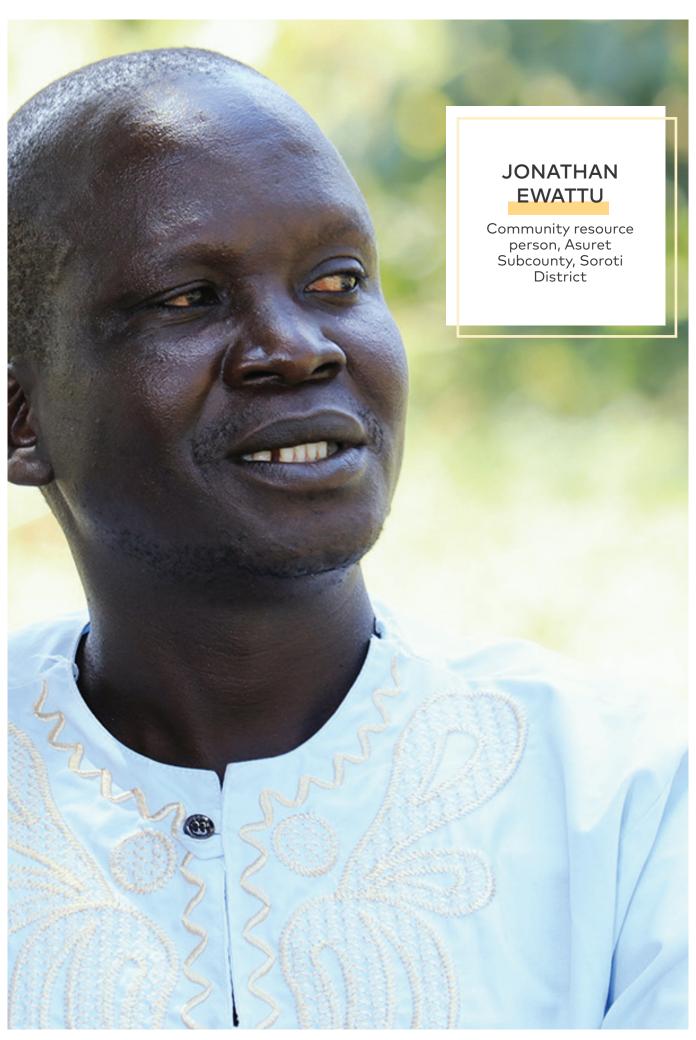
### MAPPING CHANGE

Raphael has lived in Gweri Subcounty for many years, he knows his neighbourhood well and serves as a community resource person. He is part of a wider network of people with good standing in the community such as teachers and religious leaders who raise awareness on paediatric HIV prevention and care.

Raphael supports three villages.

"At the start we created a map and placed all the homesteads on it. The area covered up to three villages, and working with the health facility, we identified children living with HIV and supported them to enrol for care, linked pregnant mothers to antenatal care and followed up missed and lost clients. As we began talking with families, we were disappointed that there were still several caregivers that did not have correct information on HIV in children, including the importance of consistent treatment. We took more time educating these families and made them feel comfortable asking questions. The community resource persons work hard to maintain confidentiality. We also divide roles to give families the attention they need."

"We took more time educating these families"

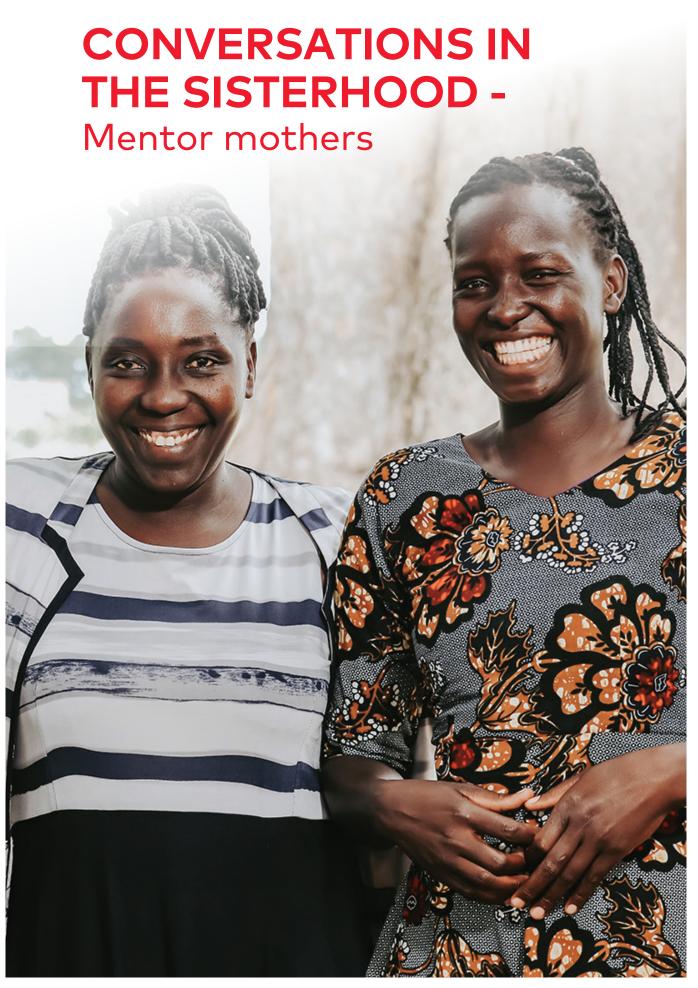


## FINDING PEACE THROUGH SUPPORT

Jonathan is a member of the village health team and the people living with HIV network in Asuret Subcounty in Soroti who was trained through the Kids to Care community intervention model and further mentored by health workers to help trace infants exposed to HIV. Sometimes the families lived far away and it meant less time for Jonathan to find work to support his own household. Jonathan was relieved he was provided with a bicycle to help with travel. He was also provided with two sheep for livelihood and was able to increase his flock, sell it and buy a cow that produces milk for his own household and to sell.

"I can leave home in peace and focus on finding exposed infants and help them get care without worrying about what my family will eat."

"I can leave home in peace"



Mentor mothers supported through Aidsfonds and partners in Soroti share their experiences on learning how to care for other mothers during their pregnancy journey.



### MOTHER OF MOTHERS-Mama Anne

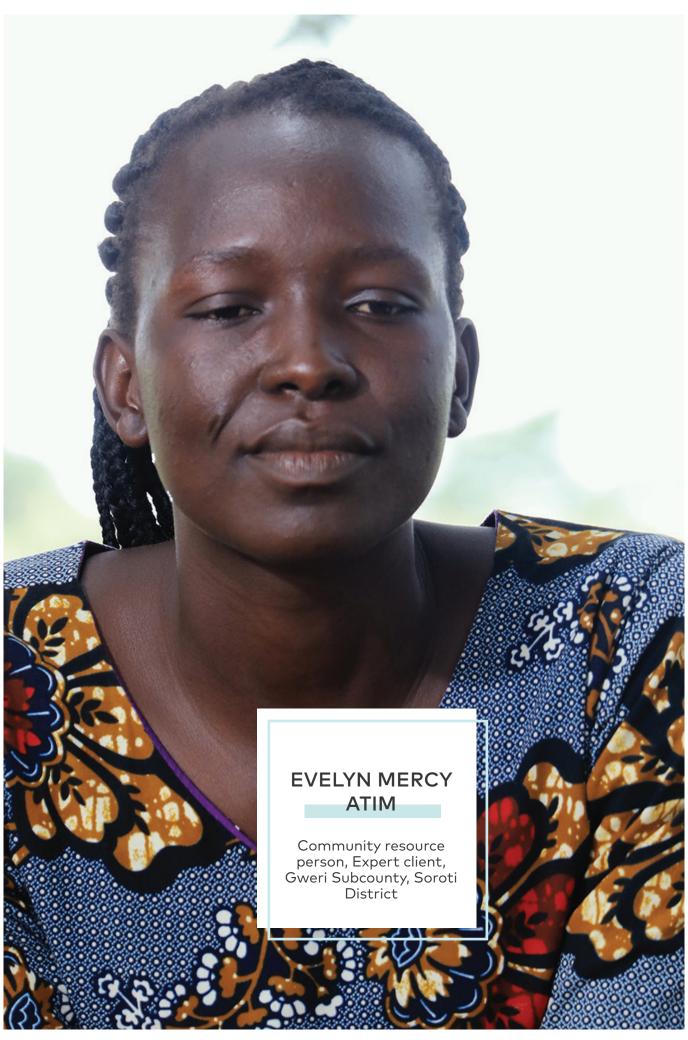
Anne is affectionately called 'mother of the mothers' by other mentor mothers.

"I support exposed infants, mothers, and their partners. Before we worked in the community, many infants got infected because of ignorance, misinformation and sometimes fear by the mothers of being stigmatised. We decided to create groups that would provide safe spaces for mothers and formed family support groups through which mothers share their experiences and encourage one another. We also use the meetings to update women on any new information on HIV prevention and care. The family support groups are good, but we also go out on outreaches in case there are mothers who are afraid to join us in the group, who have had home births or we visit new mothers that have moved into one of the villages.

Among the mothers in our care, since 2017 we haven't had any infants turn positive until recently when we went on an outreach – we found a family that had just moved here, unfortunately, the mother tested positive; her husband negative. However, he was hostile about getting care, and we did not want to put the family at risk of domestic violence. Together with male community health workers whom the husband was willing to listen to, we explained the facts about HIV with compassion. We were careful in counselling and supporting the couple and addressed concerns around transmission since they are a discordant couple. The husband tested negative. So far, the mother and baby are on treatment.

Once we have the mothers and babies doing well on treatment, we focus on other life issues through the family support groups. For example, we teach about good nutrition and with support from the community intervention we teach mothers how to make enriched porridge to build up their strength as it is rich with nutrients. We don't stop at sharing this helpful information in the family group, the intervention encouraged us to coach other mothers in the community. I have mentored two mothers to do what I do, and we work together both at the facility and with families in the community. As volunteers and mothers, we are always looking for ways to sustain our work. Through Health Need Uganda, the Aidsfonds partner in this area, we applied for and received start-up capital, formed our Village Savings and Loan Association through which we are able to borrow and lend money to improve our household income."

Anne also received three sheep which she took care of and later bought a cow, when it calved, she sold the calf and now earns money from the milk it produces. Using the money she earned and with a loan from the savings group, Anne has built a house with three bedrooms.



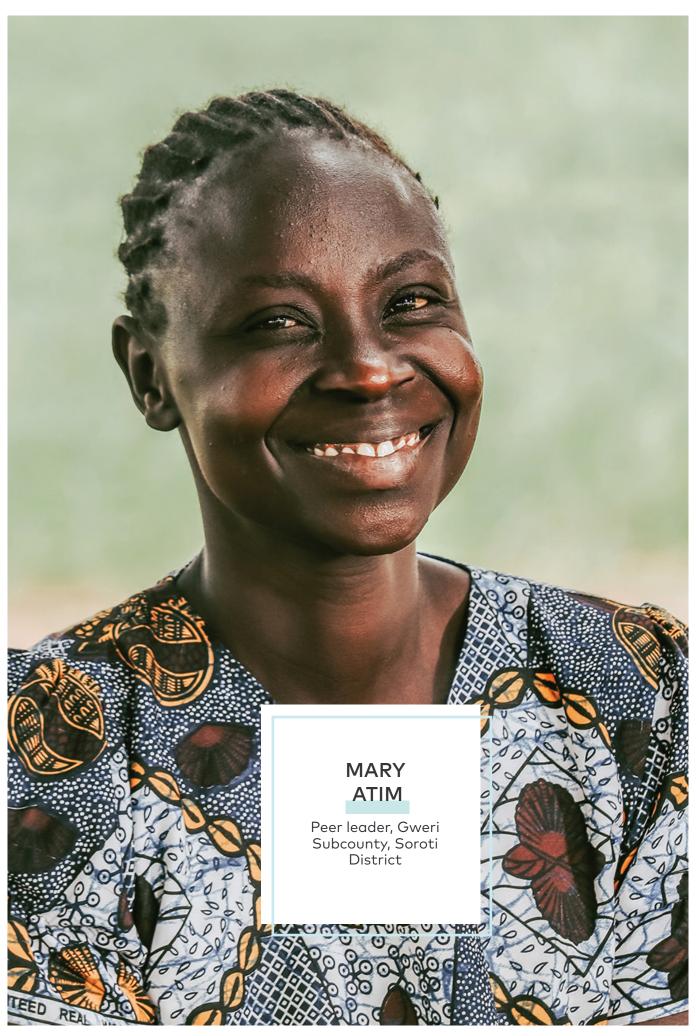
#### PAYING IT FORWARD-Mama Anne's mentee Evelyn

Evelyn is a thriving peer leader working in the same subcounty as Anne. Evelyn first met Anne at the health facility. Anne had already expressed concern about the health of Evelyn and her baby.

"I fell sick several times but had never tested for HIV. On one visit to the health facility with my baby, I finally listened to Anne's advice, I was afraid, but decided to take a test which turned out negative. On the second test [as required], I turned out to be positive and so did my baby. My heart broke and I felt so sad that I did not feel like taking the medication. But Anne did not stop checking on me and with her encouragement, I begun to accept things. Anne was kind enough to support me to talk to my husband who also got tested and turned out to be negative. She really helped us - my husband didn't leave, he stayed with us and we take precautions to maintain his negative status, and when I got pregnant again, I was able to deliver an HIV-free baby at the health facility.

I was surprised when the health facility approached me later upon Anne's referral to join the mother mentors programme. I didn't feel worthy but they encouraged me, and my life has changed for the better. I am proud to support the HIV prevention and treatment counselling teams for mothers 15-20 years and 20-24 years".

"my life has changed for the better"



#### **PAYING IT FORWARD**

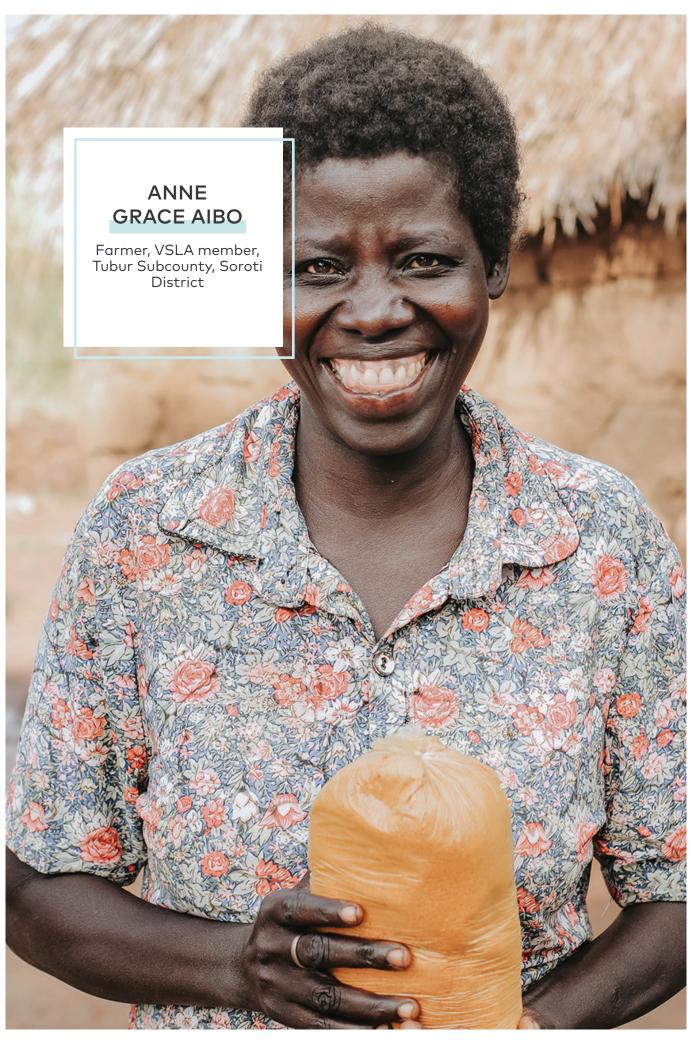
#### Mama Anne's mentee Mary

"Anne has been like a mother to us," says Mary Atim. "When I met her, I had given birth to three children and they all died but I did not know why. When I had my fourth child, he was also very sickly. One night he got so ill and we rushed him to the health centre. There was a nurse at the nutrition ward who attended to us and sent us for a blood test. Some people were whispering bad things as I took my son for the test. We both tested positive but there was a counsellor who talked to us kindly and told us what to do - we started treatment".

Unfortunately, Mary's husband left the day she disclosed their status and never returned. With the support of Anne and other women in a local family support group Mary and her child stayed on treatment. A few years later with the encouragement of her friends she got into a new relationship. This time she took him to meet the counsellor at the health centre who talked them through how to keep their family healthy and how they could live as a couple in which one partner is living with HIV while the other partner is not.

"We now have two children, a three-year-old and one-year-old. I had them at the health centre and attended all my antenatal classes and took care of my nutrition. My husband and children remain HIV negative and I am healthy and ensuring I take my medicine properly. Mama Anne and the other peer leaders in the community have supported us to live well."

"My husband and children remain HIV negative"



#### MAKING A BETTER LIVING

Anne Grace is a mother of five, and a member of one of the Village Savings and Loan Associations started through the support of the Kids to Care community intervention model. Before joining, the mother of three children living with HIV had been missing treatment appointments. The whole family's health was at risk.

"I was not consistent with my medication; I would miss some of the refill appointments for me and my three positive children. But when I joined the VSLA group the members encouraged us to keep up with our medicines. I also saved and borrowed money from the group to start up a stall selling silver fish. I am able to earn money to support my children. I don't even worry about transport now because I can afford it. We have also become healthier from the enriched porridge which we learnt to make in the group. It has helped me gain the weight you see now".

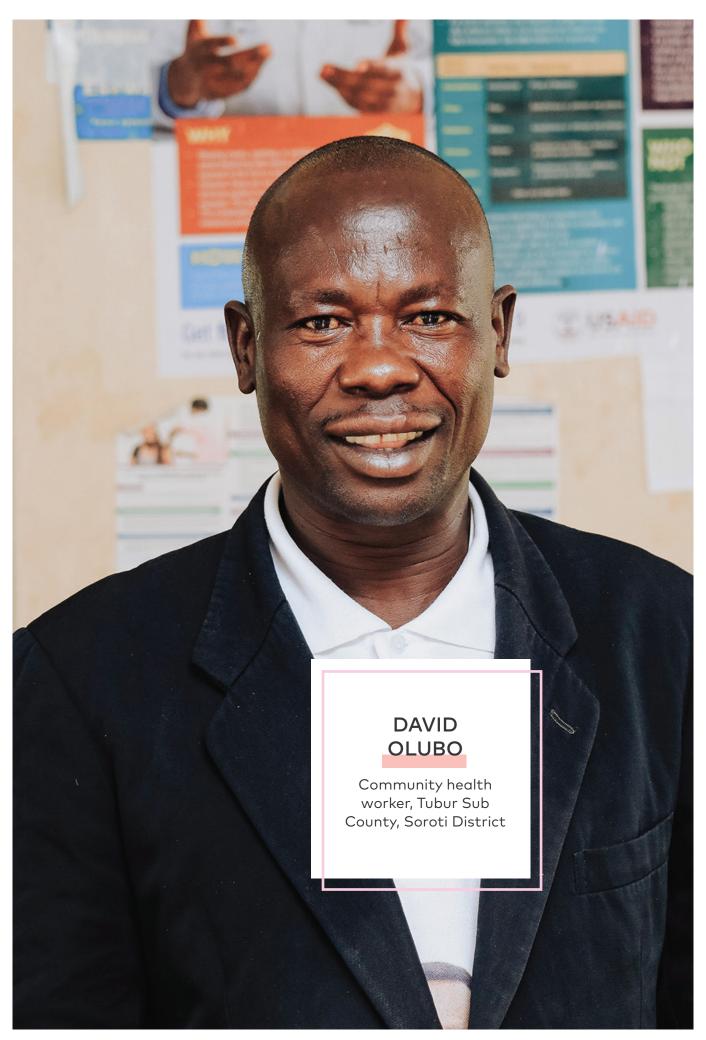
"I don't even worry about transport now"

#### **NEIGHBOURHOOD 'DOCTORS'-**

### The community health workers



Most households in rural communities know the community health worker in their neighbourhood, as they are more local than the health centre and often the first point of call for health matters. People trust their advice. Community health workers in Uganda are volunteers selected by their communities to support the Ministry of Health to bring health services closer to the people. Community health workers have been at the forefront of the HIV response for a long time and show how community strengthening is vital to HIV and AIDS programmes.

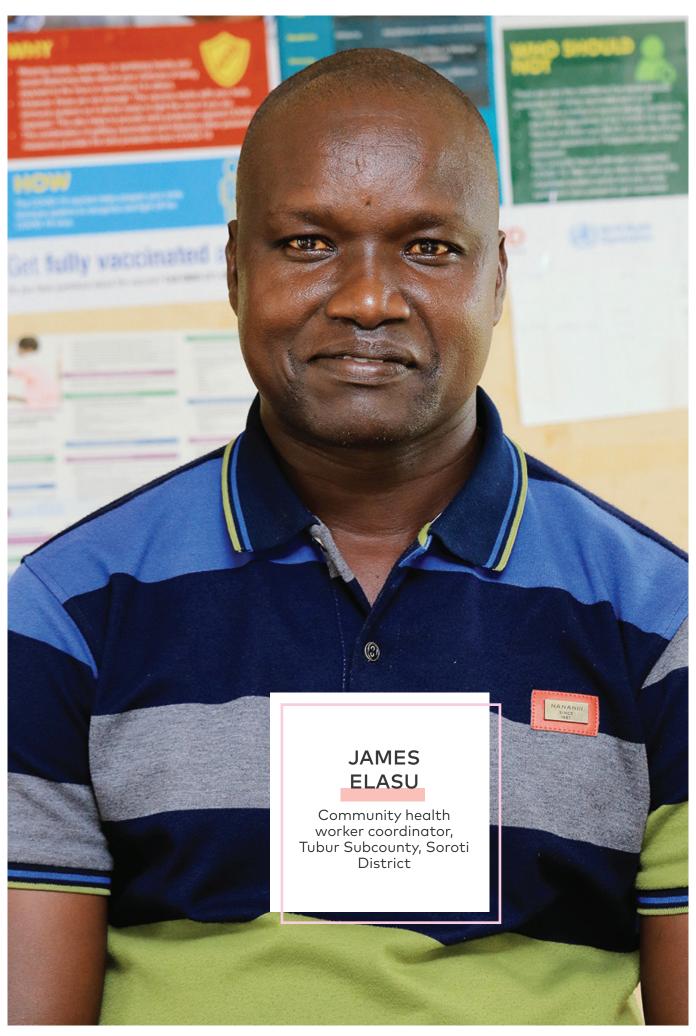


#### FINDING SELF-VALUE

David thought of himself as a "mere" volunteer responsible for mobilising his village peers around health matters. The community intervention model changed this, because it immersed the community health workers in comprehensive training on paediatric HIV as well as tracing, referral and linking clients to services. Soon, David began to see the value in his work.

"After the first training, I started with supporting children below 18 years. With my new skills, I was able to identify one within two months. The first months were not easy because there was a lot of stigma; gaining the trust of families wasn't easy. But I was proud that in a short time I used what I learnt to help a child get back on treatment."

"Gaining the trust of families wasn't easy"

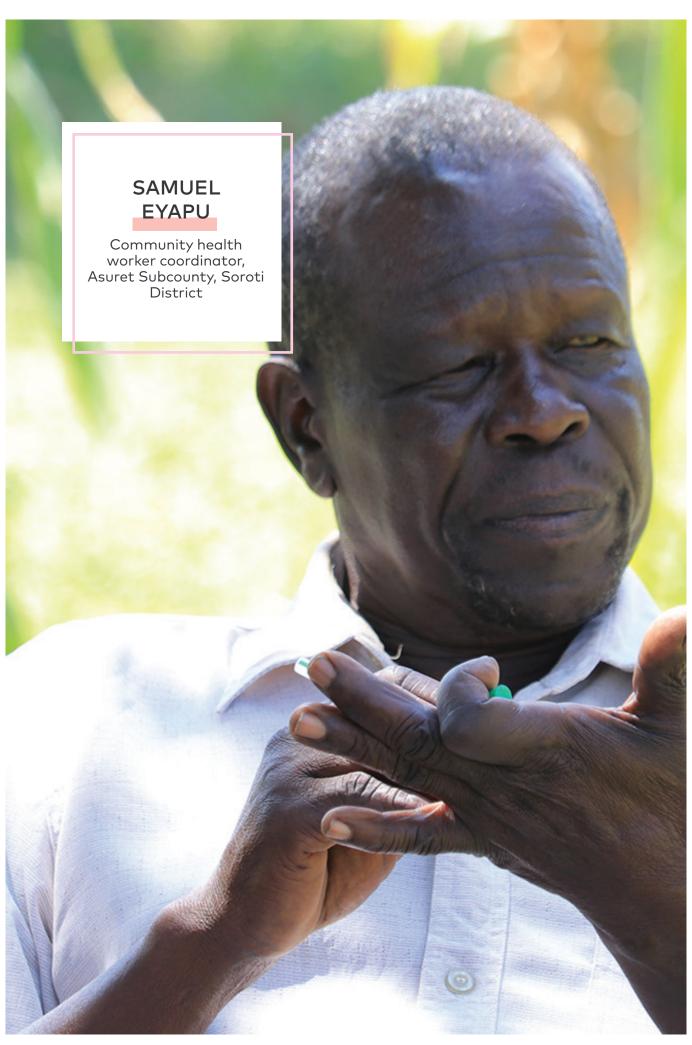


#### **BIKES FOR TRANSPORT**

James explains that community health workers were often as economically vulnerable as the families they serve. But to perform their tasks well they were required to travel long distances without much support.

"We had no transport, not enough household incomes, which made our work hard. But when we received bicycles through the community intervention, it made it easier to reach communities; they also trained and supported us to form Village Saving and Loans Associations and provided us with start-up capital. I have been a community health worker for over 10 years and this is the first time we ever got this support. Through our own savings our livelihoods have improved and we work better".

"This is the first time we ever got this support"



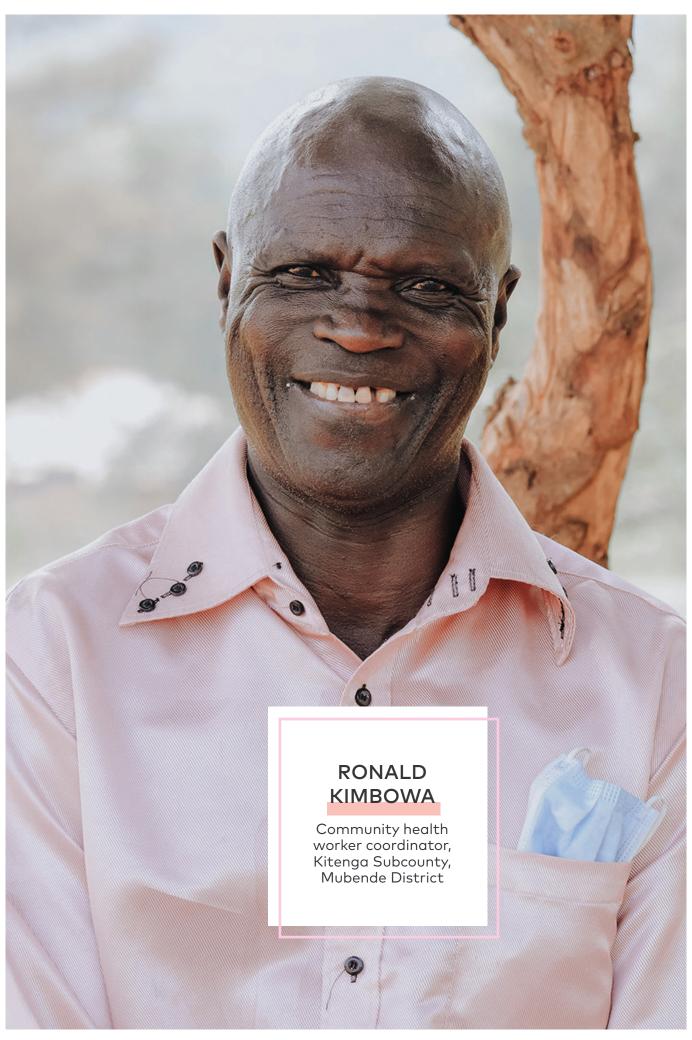
#### WHOLESOME CARE

Samuel described the difference that being a member of the local Village Savings and Loan Association has made to his life.

"Since I started working in community health, it is the first time that we have a VSLA targeting us as community health workers and others like the community resource persons. I too received a lamb and sold it and have since purchased a bull which is hired in the community for ploughing people's plantations".

Samuel is still able to work as a community health worker coordinator, and his family is well taken care of.

"It is the first time that we have a VSLA targeting us as community health workers"



#### REACHING THE CAREGIVERS

Ronald acknowledges that one of the most sensitive age categories to support and retain in care is the 0-14-year-old children living with HIV.

"Before the community intervention started it was common that caregivers did not tell their children living with HIV that they were HIV positive. Disclosure was a challenge, yet it is recommended that this is done by the time they are 12. We knew that caregivers were important in ensuring children took their medications but this group was struggling. The children who were taking their medication did not know why and many others' health was struggling due to poor nutrition and poverty among other problems. The health centre also had many patients, and health workers dispensed drugs without much time to answer questions properly. Infant tablets are many and administering them requires care but because many parents and caregivers never understood the instructions; they were not giving their children the right doses."

For Ronald this is one of the most important knowledge gaps that the Kids to Care intervention bridged.

"We were supported to create caregiver groups, learn and support each other on disclosure and administer medicines correctly. In the caregiver groups, parents learnt about nutrition, and making highly nutritious meals using local foods rich in protein and other nutrients."

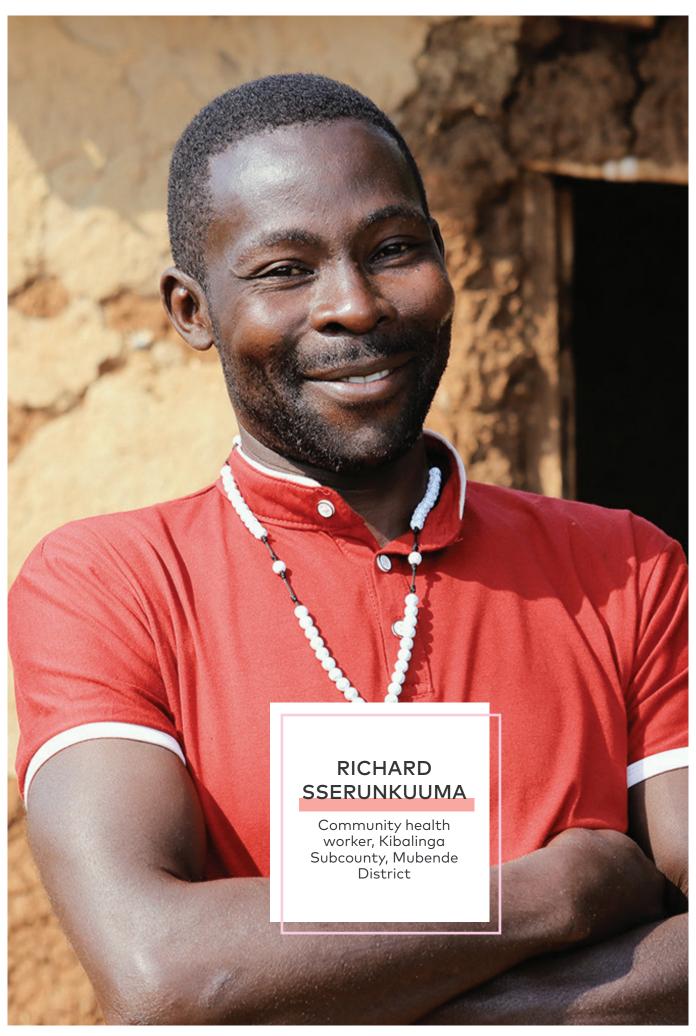
Apart from being involved in leading the caregivers support group, Ronald has also been a community health worker coordinator for years.

"For the first time me and my fellow community health workers - were provided start-up capital to create a loans and savings group for health. In the past, we complained about how expensive transport was and how we too were struggling to take care of our own household's health and wellbeing."

Ronald and the other community health workers are working on transitioning their VSLAs into a larger fund: a Savings and Credit Cooperative Organisation that can increase its profits through offering financial solutions to the community and investing in lucrative ventures.

"With regard to supporting adherence in children, we are now at over 95% in our health centre."

Ronald understands that things changed in paediatric HIV but he is confident in the support of other organisations that they are connected to, especially the National Forum of People Living with HIV and AIDS in Uganda (NAFOPHANU).

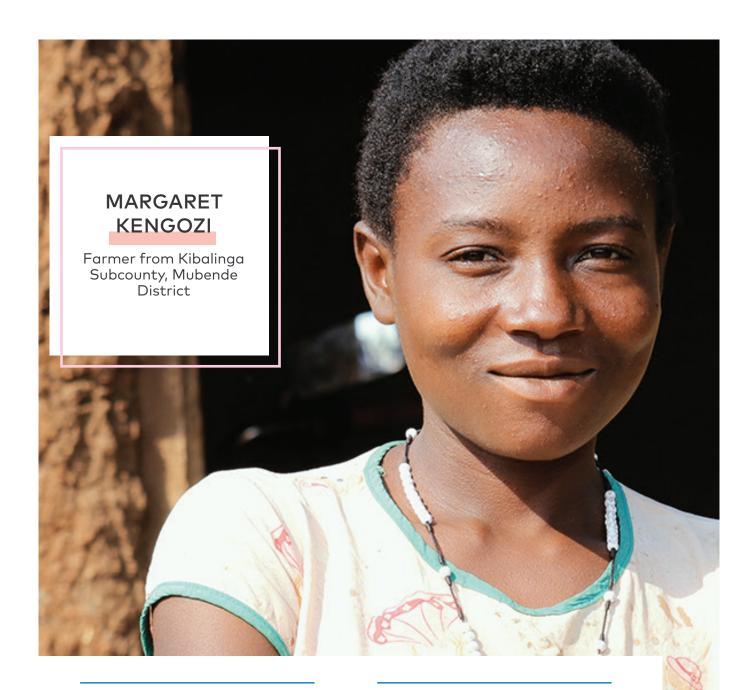


#### **BEARING WITNESS**

Richard started to work with the Kids to Care community intervention model in 2017. He was trained in paediatric HIV - follow up of children 0-14 years and expecting mothers. Richard shares one of the stories that has continued to inspire his work.

"In 2018, I used the skills to start work in the community, and that is when I identified Margaret Kengozi who had just got married and was pregnant. My aim was to link her to antenatal care services at the health centre. At the health centre, one of the routine procedures was an HIV test. It turned out positive. Margaret received counselling and we supported her to disclose her status to her husband. We invited him to the health centre for an HIV test and it was negative. The couple was taken through several counselling sessions, and they are still staying together. Margaret was enrolled on treatment and her baby was born negative."

"Her baby was born negative"



#### Margaret Kengozi sings Richards praises.

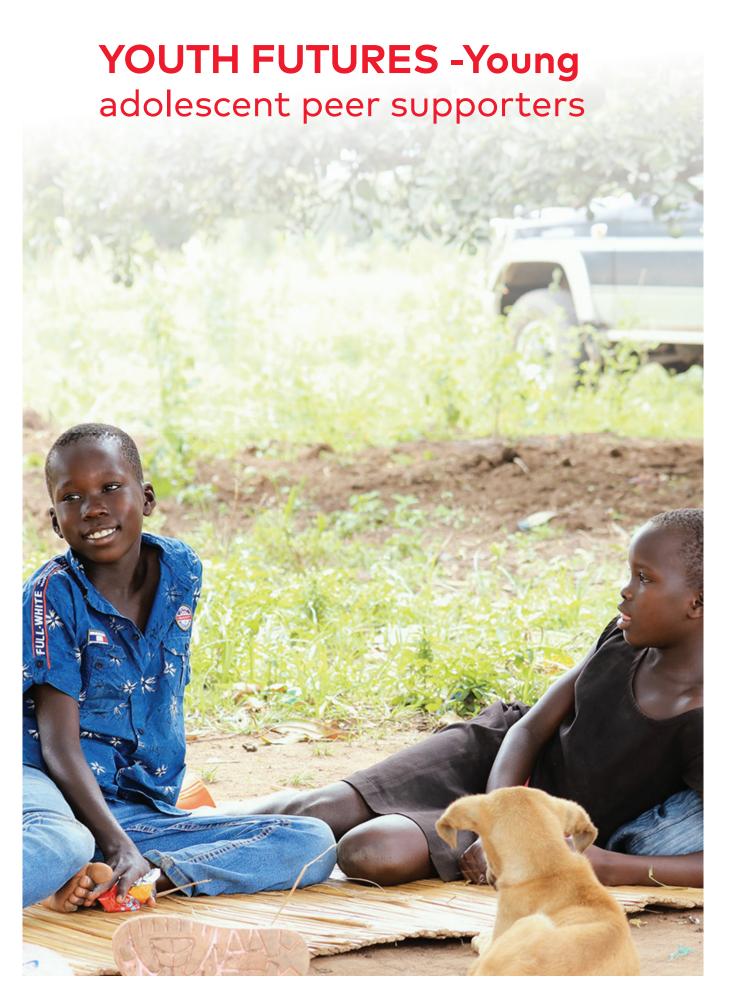
"I want to thank my 'musawo' ('community doctor') who referred me to the health centre for treatment. It was not easy for me to take in the news, but I was even more worried what my husband would say or even do, but musawo took care of that and helped talking to him. I have since given birth to another child who is also negative and hope to have a third one; but I have my first child who I had while in another area before I tested who is positive, but lives with my mother back home and gets treatment.

#### Richard returns the praises. Richard adds that:

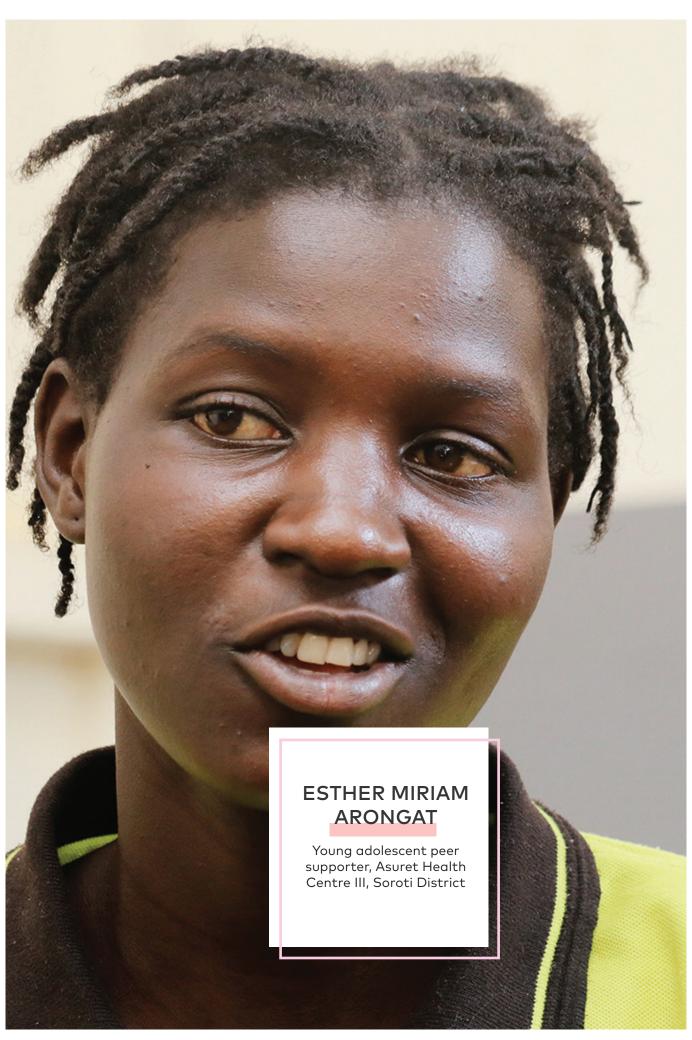
"I am proud of this couple because all the time I have spent working with communities if you find a couple when one is positive and the other negative it causes separations or domestic violence. But they allowed me to come beside them and support the family to stay on treatment and care for each other."



years we have not registered a baby born with HIV."



Young people, including young people living with HIV, lack access to sexuality information and services. Policies are often not well aligned to the reality of young people which hinders their access to sexuality education and there is a lack of youth-friendly health services. Training young community health workers or community resource persons as young adolescent peer supporters was added to the community intervention model under the Breakthrough Partnership with support from Breakthrough partner PATA (Paediatric-Adolescent Treatment Africa) to the Aidsfonds' community partners.



# YOUNG MARRIED, POSITIVE AND FREE

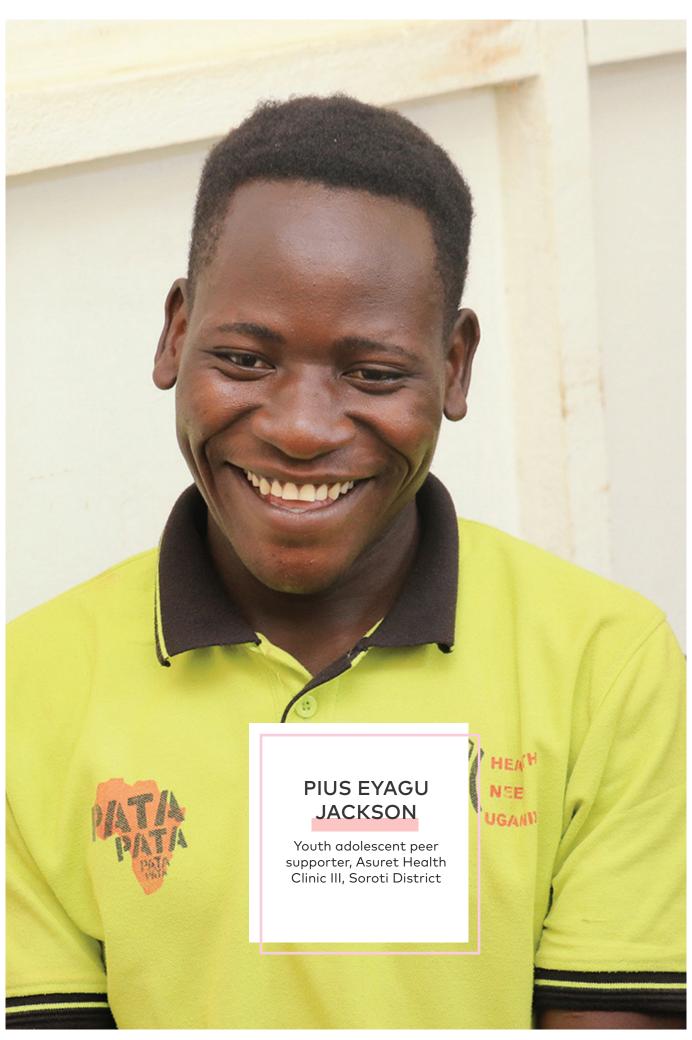
Esther contracted HIV in her teen years but did not know her status until she got married. After six months into the marriage her husband suggested the couple get tested.

"I tested positive, my husband tested negative, I was so afraid and did not want to return home with him, he too cried but with the help of the counselling we received, we have managed to stay together."

Even with her husband's acceptance Esther did not always get her treatment because she was embarrassed about going to the Antiretroviral Therapy (ART) clinic. She was worried about the health workers and others who might see her there. This finally changed when Esther was recruited as a young adolescent peer supporter. The health centre also opened a new youth corner to create a safe space where young people like her would come together to support each other in their treatment adherence journeys, share their experiences and find ways to overcome stigma. Through this initiative Esther found friends she could talk to and get support from, she was no longer afraid of getting medicine from the ART clinic as it was available at the youth corner. Today, Esther supports other youth to stay on track because she understands the struggles they face.

"I am free to say I am positive."

"She was no longer afraid of getting medicine from the ART clinic"

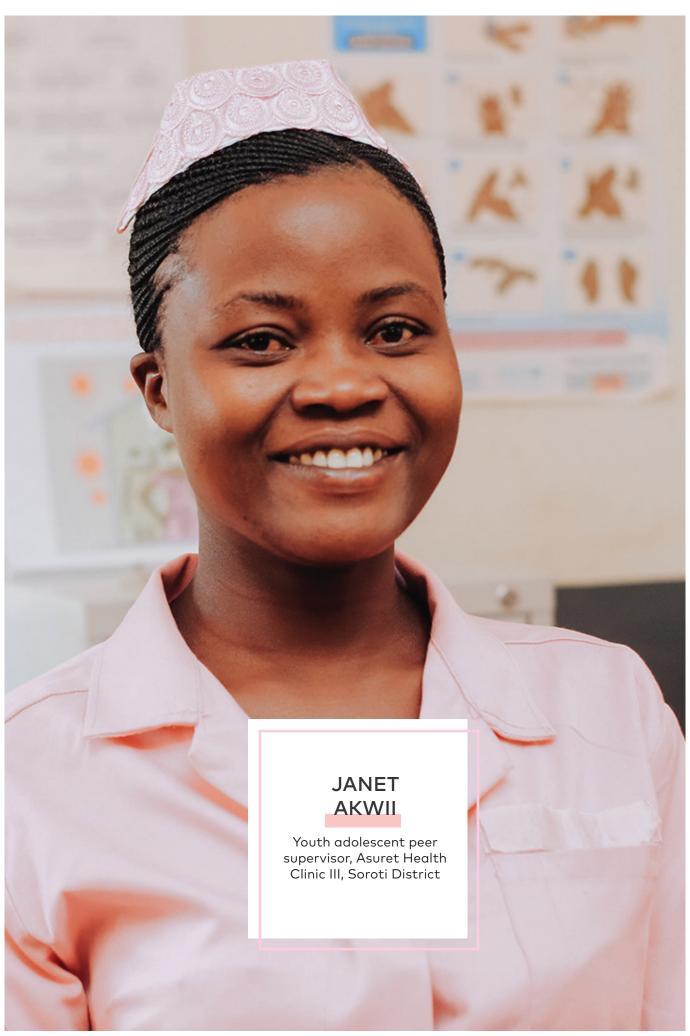


#### **BREAKING FREE OF STIGMA**

Pius contracted HIV when he was six years old. When he was younger his parents made sure he took his drugs and this wasn't a problem. But as he grew up, other students began to notice and talk about it. Pius cut a hole in his bag and hid his drugs so no one would see them. He found it hard to take his drugs even in front of those who already knew he was living with HIV. During high school, the stigma was overwhelming and he dropped out of school.

"Most children got to know I was positive, and I could not fit in, they would not want to share items with me in fear of contracting the disease. Then I joined the youth adolescent peer supporters programme, here in Asuret. I began to accept my status and learned how to carry out health education for other youths. This helped me gain confidence. We reach out to many youths living with HIV. The community intervention supports us to do this and helped us get bicycles to reach other youth who have stopped coming for treatment and who live far away".

"This helped me gain confidence"



#### A SAFE SPACE

Janet believes it is critical to find multiple ways to reach youth.

"Many young people would test positive at the ART clinic (the general clinic where everyone can receive an HIV test). They battled with unanswered questions as to why they were positive, especially when they were the only one of their siblings on HIV medication. Some never believed their results which made treatment difficult. Providing a safe space – a youth corner and peer support – has helped provide targeted follow up for the youth.

The programme has increased adherence and helped reduce stigma. We conduct school outreaches focusing on HIV which creates awareness and also helps prepare children for disclosure especially those in families that have delayed telling their children about their status. The outreaches in the community help us support young people as they start dating."

"We conduct school outreaches focusing on HIV"



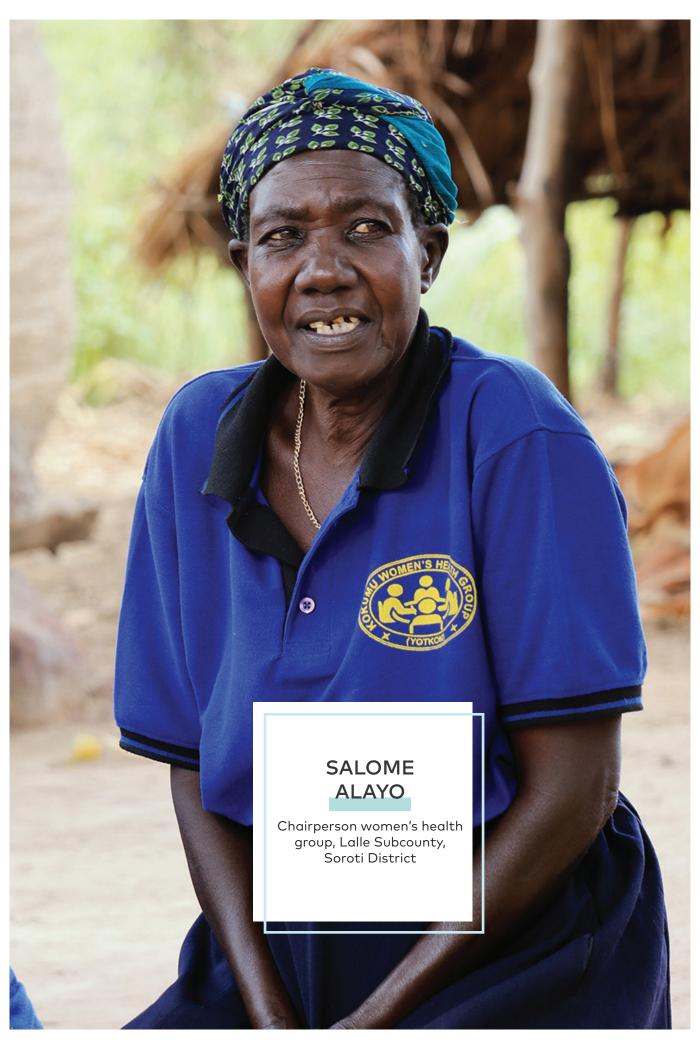


Evelyn feels that separating youth services from general services is a smart move.

"Working with youths has opened my mind to focus on their specific needs. Before, we would mix the youths with other general community clients. We would simply diagnose, prescribe medications and send them off. Through the community interventions model we learnt that youths require different approaches because of the unique challenges they face. We realised that some youths need specialised counselling, family follow ups to their caretakers and some in schools need more support such as adherence, creation of safe spaces and training teachers on how they can manage the youth living with HIV. These approaches have worked for us".

# THE COLLECTIVES -Village Savings and Loans Associations

Strengthening the role of communities in programmes targeting children affected by or living with HIV is critical. This requires bridging the gap between communities and the health systems, ensuring that community structures and resource persons are fit for purpose. Peer support groups for youth, caregivers, and mothers living with HIV are key in providing a safe space for members to share their experiences, receive health education, and support each other to adhere to treatment. The reality is that both community resource persons and families living with HIV often struggle with their own household economic welfare. Supporting them to start and sustain Village Savings and Loans Associations (VSLA) within these groups is empowering.

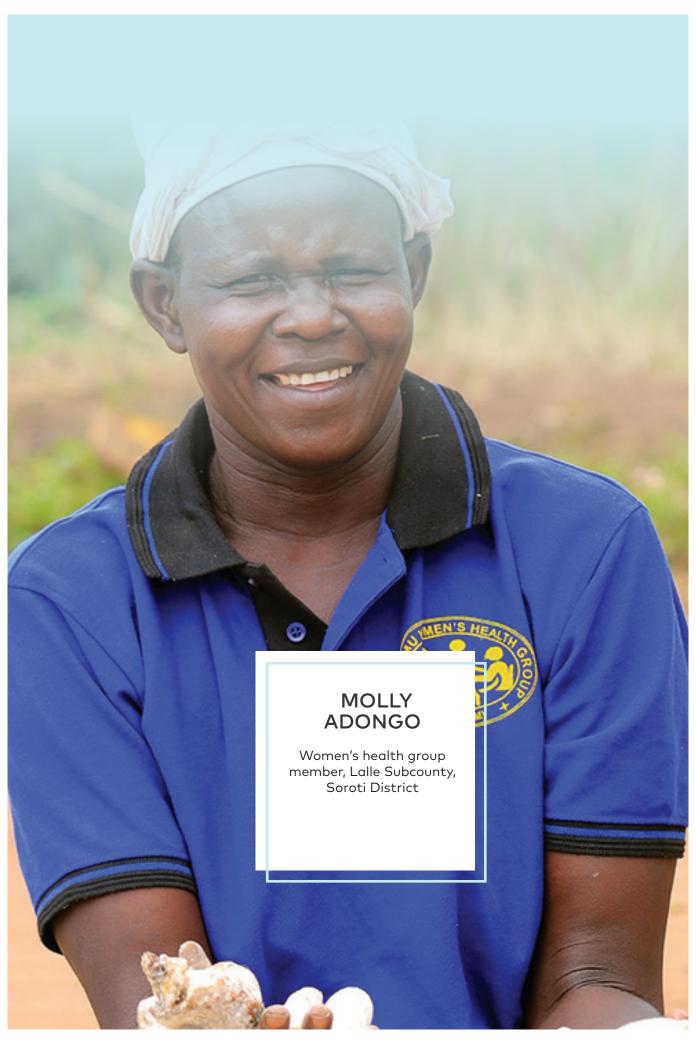


# SAVINGS FOR HEALTH IN LALLE, A GROUP EXPERIENCE FROM SOROTI

This group has 40 members - 34 women and six men. The members are all caregivers of children living with HIV.

Salome explains: "Some of us had been in savings groups before, but they failed. We didn't have enough capital to start and did not know how to manage them well. But with the community intervention model we were trained on how to start Village Savings and Loans Associations for health and how to manage them. We were also supported with start-up capital of 100 dollars, as well as key items like the cash safe and member booklets. Being involved in the group has reduced my worry for necessities such as sugar, soap, and if anyone is not feeling well we can use money saved for transport from the group and go to the health facility immediately".

"We were also supportes with start-up capital



For Molly Adongo, mother of 10-year-old twins, the group has been invaluable in helping her family adhere to treatment.

"The members have supported me in many ways, because I have children living with HIV. I would miss refill appointments because I lacked transport, at times did not have money to buy food, yet the medication required a good diet. But with the group, I can borrow from our emergency fund from which we get free interest loans and pay back at the end of the month. I also benefited from start-up capital of thirty dollars from the community intervention and an extra loan of fifty US dollars from the group. I started trading in silver fish which income helps me to supplement on food and the nutritional porridge we learnt to make."

"I can borrow from our emergency fund from which we get free interest loans"



# SEEKING LIFE ASIIKA OBULAMU GROUP IN MUBENDE DISTRICT

Jack Eigahire, the group leader shares his experience:

"We were trained on how to manage the savings associations and the community intervention provided us with start-up capital of over 200 US dollars. Members are able to borrow with interest. Personally, I have gained a lot – I bought two cows and have been able to borrow and return overtime to build a two-bedroomed house for rent which has supplemented my other income sources. We also have an emergency fund which attracts no interest to support members with urgent health needs such as transport and medication."

Yustil Kanyabuguyi the group treasurer says:

"I have two grandchildren living with HIV who are in care and we support them. I have also benefited from the group financially. I got loans to buy some fertilisers for my coffee and **my yields have since increased** which has improved my household finances."

Alice Mary Nayonga, a member living with HIV adds that:

"The group reduced our challenges: in the past we would first go to plantations where we did part time digging for pay, then we would be able to earn cash which we would use for transport to the health facility".

"Presently, as long as one saves in the group, we get transport to the health centre; this is helpful especially now that I am pregnant, and I need antenatal visits and treatment refills".

David Babona, another group member, says that the loans from the group are the cheapest he has ever received; members are not even required to provide collateral.

"If I take 50,000 shillings for a month, I only return 500 shillings for every 10,000 shillings received. This makes it easier for members to invest in profitable activities and return the loans successfully."

For Halima Nakachwa, the group is a space where she has found peace and courage.

"Above all, I have been able to give birth to two HIV negative babies, the fear I had as a positive person is no longer there because the group gives us space to talk freely, and we know we can live longer with adherence".

#### TOWARDS AN AIDS FREE GENERATION IN UGANDA PROGRAMME 2015-2022

In 2015 Aidsfonds initiated the Towards an AIDS Free Generation in Uganda (TAFU) programme designed to strengthen the role of communities in programmes targeting children affected by or living with HIV, and at the same time bridging the gap between the community systems and the health systems.

#### **Achievement Highlights:**

The community-led programme effectively created linkages between communities and health facilities; built the capacity of village health teams (community health workers) and other community resource persons such as teachers and religious leaders, and people living with HIV to raise awareness on paediatric HIV prevention and care. They also mobilised support for children and women, addressing social barriers they faced in accessing HIV services. The TAFU programme started in five rural Ugandan districts: Serere, Moroto, Napak, Mubende, and Mityana. As a result of its tremendous success. Aidsfonds funded and provided technical support for the implementation of two additional phases of the community model covering Mubende, Mityana, Kyenjojo, Ntungamo and Soroti.

#### Our partners:

Aidsfonds implemented the TAFU project in different districts with the following Ugandan non-profit organisations:

- Deliverance Church Uganda The AIDS Intervention Programme in Moroto (2015-2017)
- Pentecostal Assemblies of God Karamoja Integrated Development Programme in Napak (2015-2017)
- Health Need Uganda in Serere (2015-2017) and Soroti (2017-2022)
- Community Health Alliance Uganda in Mubende and Mityana (2015-2022) and Kyenjojo (2017-2022) Appropriate Revival Initiatives for Strategic Empowerment in Ntungamo (2017-2022)
- The National Forum of People Living with HIV/AIDS Networks (NAFOPHANU) in all above mentioned districts in Uganda and at national level (2015-2022).

For more information about the TAFU programme, visit: www.aidsfonds.org/tafu

#### 2020+

# SCALING UP COMMUNITY-LED INTERVENTIONS

# The Paediatric HIV Breakthrough Partnership

Building on the TAFU programme success, Aidsfonds is supporting the implementation of community interventions through community-based partners as part of a joint paediatric HIV response in Uganda under the Paediatric Breakthrough Partnership. The Breakthrough Partnership is a multi-year commitment to end paediatric HIV in Uganda, Mozambique and Nigeria. In this partnership, Aidsfonds is working together with the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF), UNICEF and PATA, funded by ViiV Healthcare Positive Action. All partners work across one or more service areas across the continuum of HIV prevention and care to strengthen service delivery for children and adolescents in collaboration with the Ministry of Health in Uganda. This ranges from technical support, training and quality improvements in case finding, linkage, treatment optimisation and case management. There is an emphasis on the integration of peer-led support models, with a strong focus on clinic-community collaboration, district coordination and community-led monitoring. Through strategic partnership, each partner brings complementary skills and attributes, delivering at different levels of the health system, with some overlapping and others operating in different geographic sites. Collectively, the Breakthrough Partners deliver a comprehensive service package across clinic and community platforms and leverage its learnings to inform advocacy and offer a catalytic response to ending AIDS for children, adolescents and their families.

Under the Breakthrough partnership in Uganda, Aidsfonds and Aidsfonds' partners Health Need Uganda, Community Health Alliance Uganda and the National Forum of People Living with HIV/AIDS in Uganda (NAFOPHANU) are strengthening the community response for paediatric HIV, to ensure strong health and community systems linkage, and joint advocacy for improved service delivery for children and their mothers. This is done in collaboration with the other Breakthrough Partners.









#### **R** aidsfonds