

# KEEPING CHILDREN WITH HIV ON THE TREATMENT TRACK

Yohana Mahululu is a healthy 10-year-old boy who loves to dance and play marbles. He's also lucky to be alive. His mother, father and older brother all died of AIDS over the last five years, leaving Yohana to move in with his aunt, Christina Shija, a farm worker, and her eight children. It was then he started antiretroviral treatment for his own HIV. In March 2015 Shija left home in the northern Tanzania region of Shinyanga to work the harvest season in a distant region. Her eldest daughter was left to care for young Yohana.

Three months later, Shija received an urgent call from Helena Bundala, a community health worker in her village of Kagongwa: Yohana had not turned up to collect his HIV medicine for more than three months. Since then he had fallen gravely ill with malaria and HIV-related infections. With Shija's permission, Bundala brought Yohana to the Kagongwa Dispensary to restart his HIV treatment. Within a month, his health was back to normal.



Yohana Mahululu was brought back to care by Helena Bundala

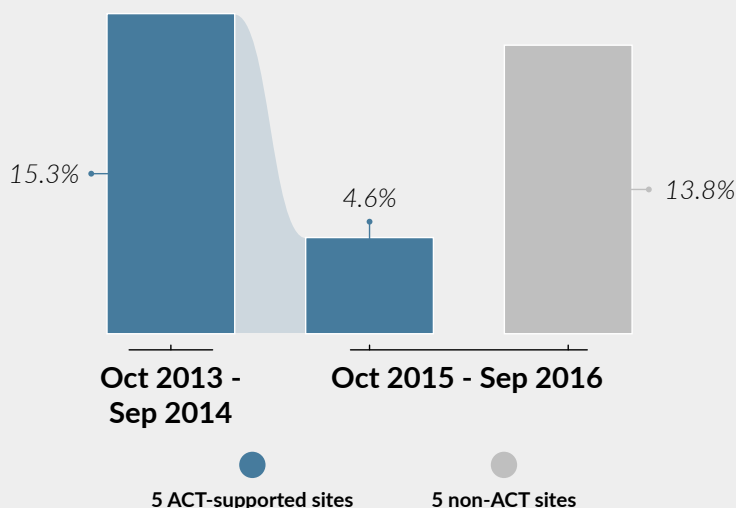


Yohana's close call is all too common among HIV-positive children across Africa. The proportion of children disappearing from HIV treatment for three months or longer—known as “loss to follow-up”—is often more than 30%, with death a frequent outcome. Reflecting those dire risks, Tanzanian health ministry protocol calls for health care workers to track down patients starting four days after they miss their first monthly appointment—*before* they become ‘lost’ to the system. Few health workers, however, make the effort before three months have passed, if at all. For children with HIV, whose fragile immune systems are easily compromised, that is too late.

All that changed for children in Shinyanga in mid-2015, when funding from the Accelerating Children's HIV Treatment (ACT) Initiative enabled health facilities to implement the four-day tracking protocol. With support from the Ariel Glaser Pediatric Healthcare Initiative (AGPAHI), the ACT implementing partner in Shinyanga, nurses started making clinical appointments for paediatric patients for the first time so they knew who was missing, and listing those names in a new tracking register. They then mobilised volunteers like Bundala, and gave them bicycles to track down missing children and bring them back into care.

Today, the tracking system provides a safety net that helps to prevent children like Yohana from falling out of care. Since ACT began in 24 facilities, almost 80% of 1,092 children missing appointments or lost to follow-up were tracked and brought back to care. Most of the remaining 20% came back on their own, although a few sadly died. The tracking volunteers “serve the lives of the children very well,” says Shija, Yohana's aunt.

## % OF CHILDREN WHO BECAME LOST TO FOLLOW-UP



Early tracking not only returns missing children, but also reduces the number of children becoming dangerously “lost” for three months or longer. In a study of five ACT-supported facilities, the loss rate in some clinics used to run as high as 26% before the program, but averaged only 4.6% in the past year—and most of those were returned to care by the trackers. By contrast, the loss among five nearby facilities not supported by the program hovered around 14%, with very few returned to care.

Children drop out of HIV treatment for many reasons. Families often don't understand the life-saving importance of staying on medication. Guardians of young orphans like Yohana may not provide stable support, and many parents do not feel able to disclose their children's HIV-positive status to them, causing children to eventually drop out of treatment because they don't understand why they're on it in the first place.



For older adolescents, stigma and discrimination cause them to avoid health facilities lest their HIV status is discovered. Indeed, for many of the children who can't be traced by the tracking volunteers, it is because caregivers intentionally give wrong contact information to elude health workers, who inadvertently raise suspicions among neighbors when they track patients in their villages.

To address these challenges, AGPAHI brings together community health workers, nurses and the government's health management teams once a quarter to share strategies for supporting vulnerable children and building trust with parents. A messaging group for all clinic personnel on WhatsApp keeps trackers and nurses in touch about missing

children and those who may have moved from one clinic to another without telling their health providers. Nurses now take time to educate children about staying on treatment with child-friendly picture books, which liken HIV drugs to soldiers who protect their bodies from enemies. AGPAHI has also trained nurses and community workers to help parents and children deal with disclosure and stigma.

The new approach to tracking sends a strong message about the importance of staying on treatment. "We'll track you when you miss your appointment, and patients know it," says Mwatano Kalova, a nurse at Kagongwa Dispensary. "Now they know they have to come."

TEXT & PHOTOS BY JONATHAN B. LEVINE  
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Community health worker/tracker Helena Bundala relies on her bicycle to track down missing children and bring them back into care.

The **Accelerating Children's HIV/AIDS Treatment (ACT)** Initiative is an ambitious \$200 million programme to put 300,000 children living with HIV on life-saving treatment in nine African countries within two years. The programme is supported by the **US President's Emergency Plan for AIDS Relief (PEPFAR)** and the **Children's Investment Fund Foundation (CIFF)**. These short cases and videos offer a mere glimpse into the complex cascade of strategies, logistics and psychology required to save children from a life-threatening disease. While all of the stories are drawn from one region, Shinyanga in northern Tanzania, and the work of only one of ACT's dozens of implementing partners around the continent – the **Ariel Glaser Pediatric AIDS Healthcare Initiative (AGPAHI)**, an indigenous Tanzanian organisation – they show the kinds of activities led by partners across the initiative.