



# Improving Anti-Retroviral Treatment for HIV-Infected Children in Uganda

Despite the rapid scale-up of prevention of mother-to-child transmission of HIV (PMTCT) programs in Uganda over the past 10 years, there are still an estimated 20,600 children throughout the country who are infected with the virus during pregnancy, childbirth and breastfeeding.<sup>1</sup> HIV-infected infants often show clinical symptoms in their first year of life. Without effective anti-retroviral treatment (ART), an estimated one-third of infected infants will die by one year of age, and about half will die by two years of age.<sup>2</sup> Although the benefits to early infant HIV diagnosis (EID) and initiation on treatment are clear, children often access HIV services late or irregularly.

In 2010, the WHO released guidelines recommending that all children below 2 years of age should be given ART as soon as they are diagnosed as HIV-infected. When the Strengthening Uganda's Systems for Treating AIDS Nationally (SUSTAIN) project started in 2010, just 25% of all HIV-infected children below 2 years of age were initiating ART upon diagnosis. The project, funded by the United States Agency for International Development (USAID) and managed by University Research Co., LLC (URC), is a five-year program that was established with three primary objectives: support the delivery of HIV/AIDS services at regional referral hospitals (RRHs) and general hospitals (GHs), enhance the quality of these services, and support increased stewardship by the MOH and the various hospitals to sustain delivery of these services.

As part of its work to achieve these program objectives, SUSTAIN is working in collaboration with the MOH to implement the WHO guidelines on pediatric ART initiation, which were formally adopted by the MOH, at the hospitals it supports. SUSTAIN's approach aims to strengthen clinical services while ensuring strong linkages for clients with community follow-up services.



A nurse counselor at Mbale Regional Referral Hospital attends to a mother and baby at the Exposed Infant Diagnosis (EID) care point.

## Intervention

At the start of the project, SUSTAIN worked with the MOH to train and mentor hospital staff in PMTCT, EID, and pediatric HIV care and treatment and to provide tools and job aides to project-supported hospitals. After the first year of activities, a review of the EID data from July-December 2011 showed that 57% of children under 2 years of age who had tested positive for HIV infection were initiated on ART, with an average of 22 days between the hospitals receiving test results and the child initiating ART. However, there were still issues with caregivers not returning for test results and routine care.

1 (2011 data) Joint United Nations Programme on HIV/AIDS, Together We Will End AIDS, 2012.

2 WHO. Antiretroviral therapy of HIV infection in infants and children: towards universal access: recommendations for a public health approach - 2010 revision. Geneva, Switzerland. 2010.

## November 2012

SUSTAIN is funded by the United States Agency for International Development (USAID) and is made possible by the generous support of the American people. SUSTAIN is managed by University Research Co., LLC (URC) in partnership with The AIDS Support Organization (TASO), Integrated Community Based Initiatives (ICoBI), Health Research Inc. (HRI), and Initiatives Inc. For more information, please contact Cordelia Katureebe (ckatureebe@urc-chs.com), Olivera Stojanovic (ostojanovic@urc-chs.com), or Kate Howell (khowell@urc-chs.com), or visit URC's website at www.urc-chs.com.

**Without effective anti-retroviral treatment (ART), an estimated one-third of infected infants will die by one year of age, and about half will die by two years of age.**

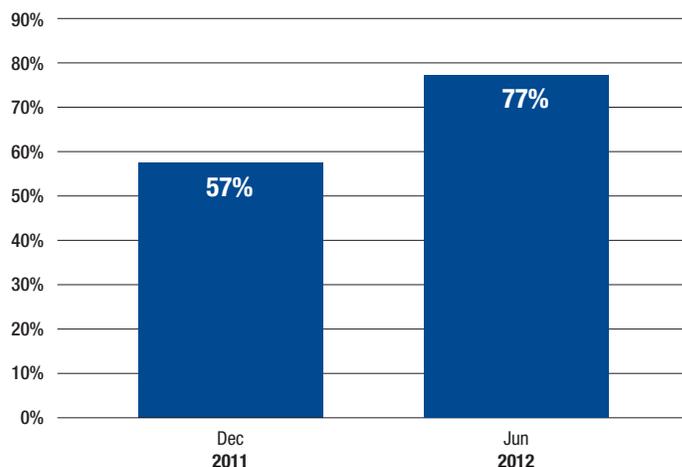
In order to better understand the factors affecting a child's likelihood to return for care, SUSTAIN conducted focus group discussions with caregivers who did not return to a health facility to receive a child's HIV test results and continue a child's care as scheduled. The following factors emerged: (1) parents not disclosing their own HIV status to their partners and subsequently having difficulties explaining to them the need for the child's follow-up visit, (2) transportation challenges, and (3) fears of an HIV-positive diagnosis. Using this information, the project was able to work with health care facilities to implement interventions for supporting early initiation of ART.

In early 2012, SUSTAIN supported teams of service providers at each of the project-supported hospitals to use quality improvement (QI) methods to improve access to care and treatment for HIV-infected infants. QI methods require teams to identify gaps, design changes that could lead to improvements, test those changes, measure the results, and then share and scale up the changes that are most effective. Teams are led through the process by trained coaches. Using this methodology, the following changes were identified as effective: identifying and linking together HIV-infected mothers who had similar challenges (partner disclosure, transportation, etc.) for peer support, distributing a letter to mothers informing them of the importance of returning to the hospital for care, encouraging partners to come with mothers for the child's care, making proactive telephone calls to follow up with caregivers, and providing targeted intensive counseling for caregivers.

## Results

After six months of QI interventions, a second review of the EID data was conducted between January and June 2012 that looked at the same indicators reviewed during the July-December 2011 assessment. Results showed remarkable improvements: 206 HIV-infected children had been identified (96 males and 110 females). The proportion of HIV-infected children initiating ART increased from 57% (140/245) in 2011 to 77% (158/206) six months later,

**Figure 1.** Percentage of HIV-infected children under two years of age initiated on ART: Comparison of 6-month retrospective reviews conducted in December 2011 and June 2012



	December 2011	June 2012
Number of HIV-infected children under 2 years of age initiated on ART	140	158
Number of HIV-exposed children under 2 years of age identified as HIV-positive	245	206

and the average number of days between the hospital receiving the HIV test result and the child initiating ART decreased from 22 days to 15 days.

## Conclusion

Improvement of health care facility factors such as pediatric anti-retroviral (ARV) drug availability and provider knowledge and skills are necessary but not sufficient to improve rapid pediatric ART initiation to the desired levels. QI approaches empower service provider teams to focus on the specific barriers that exist in their system, test targeted interventions aimed at reducing those barriers, and monitor the outcomes to quickly determine if the interventions are effective or not. Although these approaches have been successful in improving selected indicators for rapid pediatric ART initiation at certain hospitals in Uganda, some of the barriers will require community-based actions to encourage earlier HIV testing of exposed infants. However, SUSTAIN's strategy of focusing QI interventions on low-cost, feasible changes that hospitals have the capacity to implement means that wider scale-up and long-term sustainability of these changes are realistic.