

Providing Comprehensive HIV Prevention, Care, and Treatment for Children and Adults at Primary Care Centers

Promising Practices from the Elizabeth Glaser
Pediatric AIDS Foundation



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This publication is part of a series of Elizabeth Glaser Pediatric AIDS Foundation program briefs describing promising practices in HIV prevention, care, and treatment in Foundation-supported countries. A "promising practice" is defined as a practice that has demonstrated positive outcomes, but does not yet have sufficiently extensive research or replication to support generalization of the results. These promising practices often represent the synthesis of scientific knowledge and theory with practical implementation, and their dissemination is therefore critical to the advancement of evidence-informed interventions. The intended audience for program briefs is HIV/AIDS program implementers, policy makers, and donors at all levels of activity.

DISCLAIMER: The authors' views expressed in this publication do not necessarily reflect the views of the United States Agency for International Development or the United States government.

BACKGROUND

There are approximately 940,000 people living with HIV in Uganda, 130,000 of whom are children.¹ Adult HIV prevalence is estimated at 5.4% and more than half of the people living with HIV in the country are women. Despite the availability of services to prevent mother-to-child transmission of HIV, only 50% of pregnant women are currently receiving this critical intervention, leaving an estimated 40,000 women at risk of transmitting the virus to their infants.² And while antiretroviral therapy (ART) has become more widely available in recent years, an estimated 42,000 children in Uganda are still without access to these lifesaving medicines.²

The Elizabeth Glaser Pediatric AIDS Foundation (the Foundation) began working in Uganda in 2000. Since that time, the Foundation's work has primarily focused on the provision of prevention of mother-to-child HIV transmission (PMTCT) services, which the Foundation has rolled out to over 400 Ministry of Health (MOH) sites in 27 districts of the country (see Figure 1). As a result of these efforts, PMTCT services are now being offered at all levels of Ugandan health facilities—from hospitals providing complex medical care to primary care centers staffed by one nurse. This roll-out effort was guided by the principle that in order to reach those most in need, services must be brought to the facilities that the majority of individuals are most likely to access.

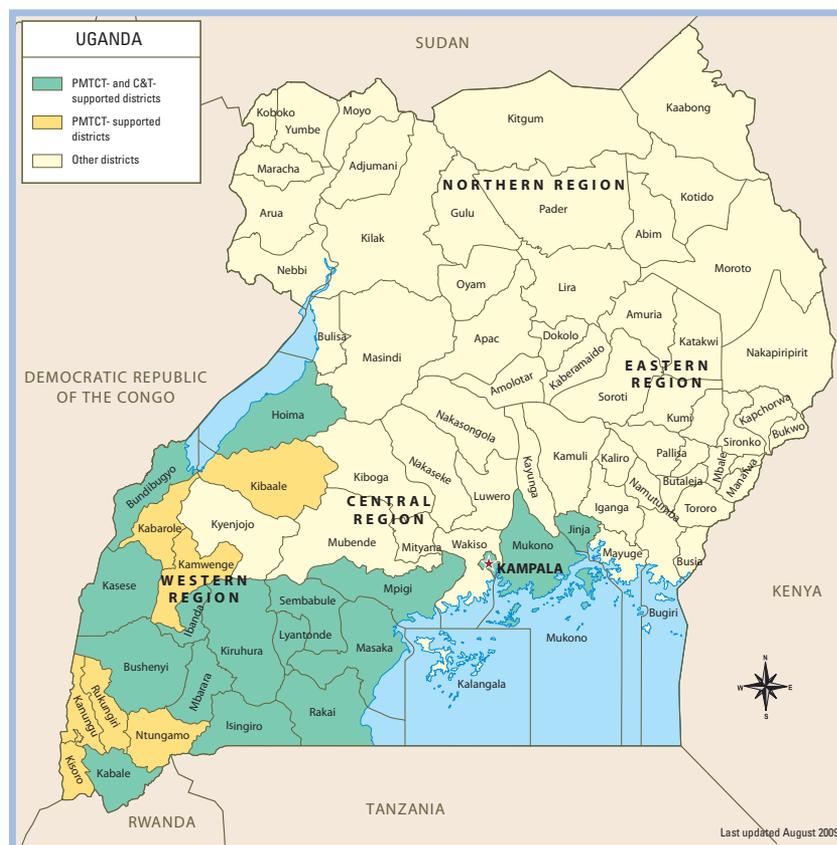


Figure 1. Foundation-supported districts in Uganda as of June 2009*

When ART first became available at government-run health facilities in 2003/04, it was primarily being offered at the hospital level. Yet access was a problem, as most women and children living with HIV are identified at the primary care level within health centers. Additionally, while many Ugandan health centers had been authorized to provide ART, they were faced with several challenges, such as staffing shortages, limited access to laboratory monitoring for patient care, inadequate training and supervision, and erratic drug supplies. In response to these challenges, the Foundation began working with the MOH in 2007 to develop innovative approaches to improve access to both ART and PMTCT while strengthening the linkages between these critical services at all health facility levels. The primary goal of these efforts was to reach more children in need of care and treatment services.

* Since June 2009, the number of Foundation-supported districts has decreased but services in these districts continue with support from other program partners.

MODEL DESCRIPTION

In August 2007, the Foundation began its efforts to address the gap in services at primary care centers in Uganda in partnership with the MOH and with ongoing support from United States Agency for International Development (USAID) through the President's Emergency Plan for AIDS Relief (PEPFAR), Abbott Fund, and other donors. Abbott Fund provided targeted private donor support for a demonstration project to strengthen linkages and enhance community engagement, which leveraged the Foundation's existing USAID-funded activities in Uganda.* Driving these efforts was an innovative model for comprehensive prevention, care, and treatment based on several key approaches (see Box 1). The model also emphasizes the importance of linking and integrating treatment and prevention to strengthen the continuum of care. With Abbott Fund support, the model was successfully piloted at five health centers in 2008, and rolled out to a sixth center in 2009.

Box 1. Key components of the Foundation's innovative model for provision of comprehensive HIV care and treatment at the primary care level

- Active follow-up of HIV-positive mothers and their children
- Accelerated enrollment of children into care and treatment
- Use of peer educators
- Community outreach and sensitization
- Infrastructure improvement
- Health worker training
- On-site laboratory monitoring

Selection of health centers that would benefit from implementation of this comprehensive model was a difficult task given the great need for provision of supplementary support to the national ART program. Following discussions between Foundation experts and the MOH, a decision was made to focus on health centers that were providing PMTCT, were accredited to provide ART, were on the national distribution list for antiretrovirals (ARVs), and had started enrolling clients into HIV care and treatment.

As of December 2009 the program was covering health centers in Masaka, Kabale, Mayuge, Mukono, Bushenyi, and Jinja Districts of Uganda. When the program was first launched, HIV services at these sites were limited to HIV counseling and testing, PMTCT, and basic HIV care. One year later, every site was offering a comprehensive range of HIV services, including ART and psychosocial support for children and adults. Vast improvements had also been made to clinic infrastructure and staff capacity, which served to strengthen overall service delivery. A summary of activities conducted during 2008 and 2009 in the six districts covered by the program is presented in Table 1.

ACTIVE FOLLOW-UP OF HIV-POSITIVE MOTHERS AND THEIR CHILDREN THROUGH FAMILY-CENTERED, HOME-BASED CARE

Home-based care services are offered through the ART, PMTCT, and maternal and child health (MCH) clinics. The selection of clients for home-based care is carried out by clinicians and nurses stationed at these service delivery points. To improve the tracking of clients for subsequent follow-up, home-based care teams, comprised of both

* Further details about the Call to Action project, including the activities implemented in Uganda with USAID funding, can be found in the final program report (Elizabeth Glaser Pediatric AIDS Foundation (EGPAF). Call to Action End of Project Report, 2002-2010. Washington, DC: EGPAF; 2010.) available on the Foundation's website.

Home-based care activities have reduced the proportion of clients lost to follow-up from 95% to 15% at participating sites and have increased the number of families returning to collect infant PCR test results.

health-care workers and peer educators, record and bring back information to the clinic about individual patient status and new appointment dates. This has been shown to increase the number of families returning to collect DNA polymerase chain reaction (PCR) results for their infants, and has reduced the proportion of clients lost to follow-up from 95% to 15% at participating sites (as of December 2009).³ The team's activities are particularly focused on the delivery of pediatric-specific interventions. For example, HIV-positive pregnant women newly diagnosed in antenatal care (ANC) are attached to peer educators, with an aim of establishing bonds that will enhance follow-up of these mothers from that point until after delivery. This link provides clinic staff with direct access to HIV-exposed infants so that they can provide early infant diagnosis and, if needed, appropriate pediatric care and treatment.

Services offered during home-care visits include delivery of medicines for HIV treatment and PMTCT, prescription refills for routine prevention of opportunistic infections (OIs), counseling on infant feeding, HIV status disclosure support, HIV testing for household members, and referrals for family members found to be HIV-positive. The visits also target PMTCT clients who have not returned for the PCR test results of their infants.

A home-visit guide was adapted from MOH home-visit guidelines and simplified so as to be appropriate for use by peer educators. These guidelines include criteria for the identification of individuals, including children, who may require active follow-up. A diary system is used by the home-care team to track client appointments and other key treatment-related milestones, such as expected dates of delivery for HIV-positive women and ARV refill appointments. This information is then used by care teams to schedule follow-up activities.

ACCELERATED ENROLLMENT OF CHILDREN INTO CARE AND TREATMENT

Stationing peer educators at key entry points within the well-child clinic has enabled the identification of HIV-exposed infants whose mothers are then guided to where additional counseling and patient education are provided. Peer educators identify families in need of services by routinely reviewing the child health cards for mothers' HIV status. If this information is missing, the peer educator approaches the mother to obtain her HIV status and records

Table 1. Summary of Program Activities in the Six Districts (January 2008–December 2009)

Activity	Total
Training	
Health workers trained in ART	125
Health workers trained in (non-ART) HIV palliative care	84
Community members trained in (non-ART) HIV palliative care	341
Community	
Home visits to provide HIV counseling, testing, and care	1,208
Members of Ariel Children's Clubs: psychosocial support for HIV-positive children	1,176
HIV Counseling and Testing	
Adults counseled and tested	14,138
Children (<15 years) counseled and tested	1,063
HIV Care and Treatment	
Adults enrolled in HIV care (cumulative)	5,126
Children (<15 years) enrolled in HIV care (cumulative)	1,188
Adults initiated on ART (cumulative)	988
Children (<15 years) initiated on ART (cumulative)	73

Psychosocial support services for HIV-positive children and their families are now a routine part of clinical care and treatment services at all six health centers.

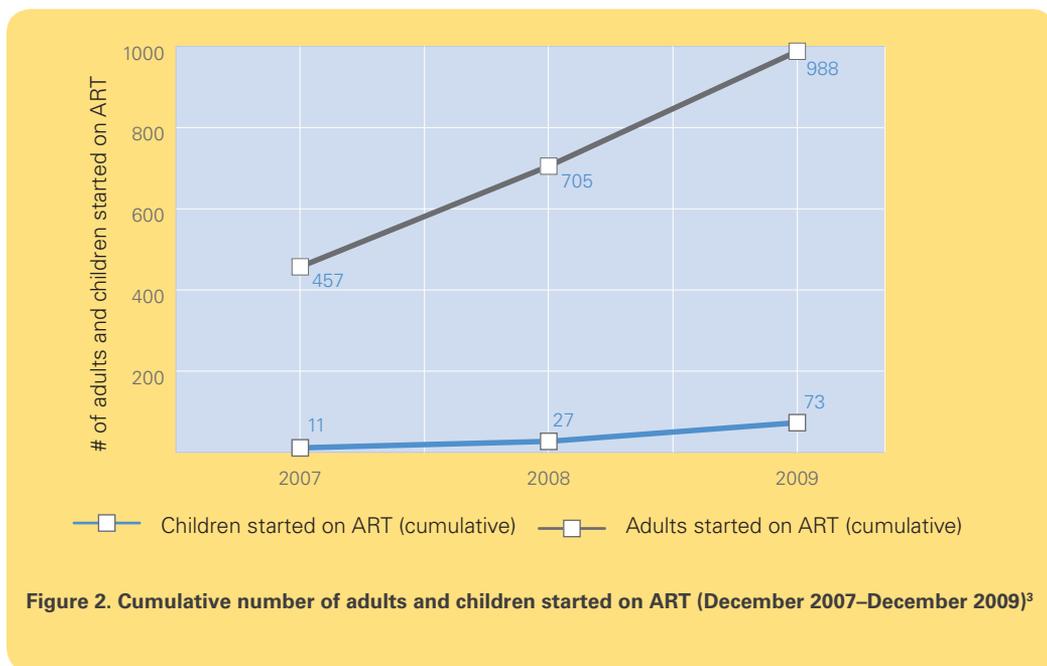
it on the card. From January 1, 2008, to December 31, 2009, a total of 1,137 mother-infant pairs were identified and 1,112 HIV-exposed infants were tested. Of those tested, 100 infants were found to be HIV-infected and were subsequently enrolled into care.³

A total of 988 adults and 73 children have been initiated on ART since the program’s inception (January 2008 through December 2009; see Figure 2).³ Technical support provided by the Foundation to the implementing sites is focused on improving ordering of supplies for pediatric care. Additional supplies of OI medications procured through donor support have also improved the consistency of drug supplies at the clinics.

Improved linkages between the different HIV care entry points for children have enabled the tracking of individual cases and have facilitated enrollment.³ To provide ongoing psychosocial support to children enrolled into care and treatment, Ariel Children’s Clubs have been initiated at all six sites. HIV-positive children on ART, as well as those enrolled into care but not yet eligible for treatment, have the option of joining the clubs. Membership in the Ariel clubs is optional. The broad objective of the Ariel clubs is to enable HIV-infected and affected children to live a quality life. “Quality life” is defined as when a child’s psychological, physical, spiritual, and social needs are being met. Psychosocial support services for HIV-positive children and their families are now a routine part of clinical care and treatment services at all six health centers. The singing and drumming during Ariel Children’s Clubs have proven to the surrounding communities that HIV-positive children can do well on treatment and live happy and productive lives. A total of 1,176 HIV-positive children are members of Ariel clubs, which meet once a month. Ariel holiday camps, where children spend a week together, occur twice a year and are open to all members of the Ariel clubs.

USE OF PEER EDUCATORS TO PROVIDE CLIENT COUNSELING AND SUPPORT

A key innovation of this program has been the involvement of people living with HIV in counseling clients at the clinics and during home-care visits. Key duty stations for peer educators are the antenatal clinic, well-child clinic, and ART clinic. Through a process of experience sharing and mentoring, the peer educators help clients to cope with





Members of the Ariel clubs celebrate World AIDS Day.



Women take part in the community gardening project.



Extension of the outpatient block where the new laboratory is located (darker red section of roof).

the challenges of living with HIV. The emphasis during these visits is on disclosure, adherence to treatment, infant feeding, and self-stigma reduction. Male peer educators have been especially instrumental in helping HIV-positive women to disclose their status to male partners by directly engaging with and sensitizing male partners, who are often the primary decision-makers in the Ugandan family setting. As of December 2009, 146 women had requested and received support for disclosure of their HIV status to family members.³

The peer educators program continues to improve the active follow-up of individuals living with and affected by HIV. As of December 2009, 3,331 clients had been attached to peer educators.³ This program ensures that HIV-positive individuals receive supportive counseling and mentoring from the more senior clients, and the bonds that develop between clients and mentors facilitate clients' return for follow-up care. Peer educators are selected from among parents living with HIV (mothers and their male partners) identified in PMTCT programs and are assigned specific, nonclinical roles and trained alongside professional health workers at participating sites.

Full participation of peer educators in the health facility and outreach services has expanded each site's ability to provide quality care by allowing the already overburdened health workers to concentrate on more technical tasks. For example, consenting clients are attached to a peer educator, who provides an orientation on available services and guides clients to the next service point. These activities have been observed to reduce client waiting times at the clinics.

COMMUNITY OUTREACH AND SENSITIZATION

Community outreach activities include HIV counseling, testing, adherence support, and tracing of clients lost to follow-up. Home visits are conducted once a week by both peer educators and health workers. School visits by joint health-care worker-peer teams are conducted to support ART adherence for children in boarding schools. Children with known drug adherence problems and those who report challenges at school are followed up at school, where counseling is provided to increase their motivation to take their prescribed medications and to provide support for other treatment-related challenges.

Through the USAID-funded Health Initiatives for the Private Sector (HIPS) Orphans and Vulnerable Children (OVC) program,* 207 caretakers of HIV-positive children have been trained in various income-generating activities.³ Gardening projects have been started at each of the participating sites to demonstrate simple farming techniques that will enable caretakers to enhance household food security and improve the nutritional intake of HIV-affected and infected children. Other skills that are being taught include knitting, plaiting hair, and making handicrafts. Under the HIPS program, a total of 139 children have received scholastic materials and other school fees (as of December 2009).³

Linkages have been established with existing community-based programs to increase the screening and identification of HIV-exposed children. Consultations with local community leaders have helped establish an environment in which outreach teams can more easily sensitize and mobilize communities to utilize the available HIV care and treatment services for children. Community-based organizations, and specifically groups of people living with HIV, have been recruited to work together with health facility staff to provide HIV counseling and testing and health promotion in the community, and to participate in community dialogues during outreach activities. Ongoing community sensitization about the new services has increased referral of pediatric and adult cases to the health facilities. The joint

* The HIPS Project, launched on April 22, 2008, is a USAID-funded project that works with the Ugandan business community to find cost-effective ways to ensure access to and utilization of vital health services for company employees, their dependents, and the surrounding community members.

health worker–peer educator home-care teams have strengthened linkages between the health facilities and the communities.

INFRASTRUCTURE IMPROVEMENT

Efforts have been made to strengthen clinic infrastructure, train staff, and streamline service delivery at all six sites. Activities are focused on curriculum development and training, instituting mechanisms to follow up HIV-positive mothers and enroll children into care and treatment, maximizing staff capacity through task shifting, and remodeling poorly functioning laboratory and clinic spaces. Through a participatory planning process with the health facility staff, the HIV care clinics were reorganized to improve efficiency of staff assignment, client appointments, filing systems, and the requisition of medicines and supplies. Each site has regular case management meetings that focus on the clinical progress of individual clients, relate it to the individual patient's social circumstances, and evaluate individual cases for active follow-up, including home visits. In order to ensure effective and sustained improvement in the quality of services provided, a staff training program was initiated (see following section on health worker training).

HEALTH WORKER TRAINING

Health-care workers have been trained by Foundation technical advisors and MOH staff using the national curricula for HIV care, provision of ART, rational drug use, and pharmaceutical management, including ordering of ARV medicines. Clinical officers, who provide the bulk of HIV care at each of the six HIV care and treatment sites, have been the focus of capacity building. A curriculum tailored toward this intermediate cadre of clinicians was developed by the Foundation in conjunction with the MOH, and training began in 2008. Through mentoring and attachments to regional hospitals, these clinical officers now form the backbone of HIV clinical care at supported sites.

Training is targeted at building health-worker capacity where gaps in knowledge have been identified. For example, due to recent changes in national treatment guidelines for children, training is focused on early initiation of ART in children, as well as early infant diagnosis of HIV and methods to ensure that HIV-infected infants are linked with HIV care and treatment services. In order to improve the uptake of PMTCT services, site personnel are trained in the repackaging of nevirapine suspension for home dispensing of ARV prophylaxis to the newborn infants of HIV-positive women. Another identified area of need was data management and reporting. Data clerks were therefore trained in various aspects of HIV data management and electronic data reporting tools based on the national ART program paper record.

ON-SITE LABORATORY MONITORING

Patient monitoring is now a well-established practice at all six sites and quality of care has improved. New patients can get the required baseline tests done during ART enrollment; patients enrolled prior to initiation of these services are now getting routine tests done at the facility according to schedule. The patient record systems have been streamlined and sites are now able to generate electronic reports that identify patients requiring critical laboratory investigations, such as CD4 counts to monitor HIV disease stage and liver function tests to detect potential adverse effects of ARVs. Laboratories at each of the clinics have been provided with basic laboratory equipment and supplies, allowing for TB testing, complete blood counts, and hemoglobin counts to be performed in-house; CD4 and liver function tests are carried out at five referral laboratories to which blood samples are sent. This system has enabled hundreds of patients to obtain laboratory services that were previously inaccessible to them and allows clinicians to make better-informed treatment decisions based on clinical evidence.

KEY CONSIDERATIONS

CHALLENGES

- While systematic identification of eligible children has improved and supplies of pediatric ARV formulations within the national ART program are being received, the program remains concerned about the stability of the drug supply chain.
- Health-care worker attrition rates and staff turnover are high. Orienting and mentoring new staff in order to keep program performance on track uses up valuable time and resources.
- While the turnaround time for the return of DNA PCR results for early infant diagnosis has been reduced, greater efficiency is required to improve client confidence in the system so that families return to collect their infants' test results.
- The impact of community campaigns to increase the demand for pediatric HIV care services is negatively affected by delays in providing families of HIV-exposed infants with a timely diagnosis.

RECOMMENDATIONS

- The Foundation should continue providing technical assistance to the MOH to further strengthen the drug supply chain.
- Integrated Management of Childhood Illness (IMCI)-based strategies for identifying and initiating care for HIV-positive children at participating health facilities, coupled with development of client-flow job aids for pediatric care, can strengthen services for HIV-exposed and infected children at primary care centers.
- By the same token, use of well-child services in high-HIV-prevalence settings as an entry point to care, coupled with specialized training programs, can improve case finding and follow-up of HIV-exposed children. Offering as many of these services as possible within a single visit would improve program efficiency and encourage enrollment of eligible children.
- Supplementary funding from nongovernmental sources should be used to effectively improve the delivery of complementary HIV care and support services at primary health-care facilities.
- Operations research should be used to formulate solutions to the various challenges cited in this report. For example, more research is needed on mechanisms to ensure that improved diagnostics and treatments for HIV-positive children will translate into equitable access to these services for the most affected populations.
- Following on the success of the home-based care intervention, follow-up of enrolled clients should be integrated into the MOH "Village Health Team" strategy. This would ensure a more sustainable approach to the provision of supportive care to families affected by HIV.
- The MOH should adopt clinical mentorship as one of the standard training approaches used in Uganda.

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