

A Review of CRS' Programs for Children Living with HIV

A qualitative
analysis

Mychelle Farmer
Jamie Lynn Mignano



EVALUATION

Copyright © 2011 Catholic Relief Services

For any commercial reproduction, please obtain permission from pqpublications@crs.org or write to:

Catholic Relief Services
228 West Lexington Street
Baltimore, MD 21201-3413 USA

Other CRS technical materials are available at www.crsprogramquality.org

Cover photo: David Snyder/CRS

A REVIEW OF CRS' PROGRAMS FOR CHILDREN LIVING WITH HIV

A qualitative analysis

TABLE OF CONTENTS

Acknowledgments.....	iii
Executive Summary	iv
Abbreviations.....	vi
Background	vii
Epidemiology of Perinatal HIV Infections	1
Clinical Interventions to Reduce Mother-To-Child Transmission of HIV.....	4
Description of Program Analysis	7
Methods	9
Results/Analysis	12
Conclusions.....	21
Appendix: Interview Guide	23
References	28

ACKNOWLEDGMENTS

This evaluation of pediatric ART programs was supported through the generous private donors of Catholic Relief Services. The evaluation would not have been possible without the many valuable contributions of CRS staff, including Shannon Senefeld, Michele Broemmelsiek, Herby Derenoncourt, Karen Moul, Naomi Van Dinter, and Carrie Miller. Regional support was provided by AIDSRelief Regional Advisors, including Tina Monique James, Leia Isanhart-Balima, and Meredith Stakem.

The authors also wish to thank those who took the time to complete the pediatric ART questionnaire. This group includes the following people:

Dr. Desire (Burundi)
Dr. Chalumeau and Dr. Robert Pierre (Haiti)
Ms. Rose Owiny, Sr. Mary odundo, and Ms. Lucy Nyaga (Kenya)
Dr. Steve Amodu, Dr. Chris Nwaforji, and Dr. Fatima Hassan (Nigeria)
Sr. Yvette Vincent (Rwanda)
Dr. Delphin, and Dr. Mjema (Tanzania)
Dr. Martin Ogwang, Dr. Maria Nannyonga, and Dr. Cyprian Katookye (Uganda)
Dr. John Spurrier, Dr. Elisa Faceli, and Mr. Jackson Mapulanga (Zambia)

EXECUTIVE SUMMARY

Catholic Relief Services (CRS) has engaged in successful programming for people living with HIV (PLHIV) and their families over the past two decades. This report highlights the organization's contributions to programs that support comprehensive services for children infected with HIV.

Since 2004, CRS has participated in a five-member consortium, AIDSRelief. This consortium includes the University of Maryland School of Medicine's Institute of Human Virology (IHV) as the clinical leader and Futures Group International as the leader for strategic information support. Along with CRS, there are two other faith-based organizations within the AIDSRelief consortium: IMA World Health (IMA) and Catholic Medical Mission Board (CMMB).

Through AIDSRelief, Catholic Relief Services works in close collaboration with clinic-based and community-based partners in many countries that are experiencing significant challenges caused by the HIV pandemic. AIDSRelief and CRS strive to build capacity within the local partner organizations so that they might meet the needs of children and families affected by HIV.

This report highlights the work accomplished by selected local partners in treating children living with HIV. Most of CRS' partners who provide HIV treatment to children are supported by AIDSRelief (which is funded through the President's Emergency Plan for AIDS Relief (PEPFAR)); however, a small number of programs are funded through other agencies. Overall, AIDSRelief provides HIV care and treatment in over 200 clinical centers. Over 18,000 children receive HIV care and treatment in AIDSRelief sites. The consortium works closely with the partners to develop programs that ensure high-quality care that results in improved health outcomes for children living with HIV.

The information provided by our local partners indicates many positive aspects of CRS-supported HIV programming. The local partners indicate there are many program strengths, particularly for programs supported by the AIDSRelief consortium. Partnerships with local organizations facilitated access to high-quality comprehensive care and treatment. Access to care was strengthened at the clinical level and at the community level. Children benefitted from adherence support, and family-centered care was enforced through many components of the care plan. The local partners were able to make significant contributions to the care of children living with HIV, and they received support that allowed scale-up of services over time. Today, over 8% of the PLHIV who are receiving care and treatment through AIDSRelief are children.

This report also describes the challenges faced by pediatric antiretroviral therapy (ART) programs. CRS and its consortium partners seek to achieve sustainable interventions that are consistent with the best practices acknowledged by agencies worldwide. Local partners are trained in approaches to care that are

endorsed by national guidelines and by the WHO, U.N. and PEPFAR. As these programs mature, pediatric ART will remain an important component of their health programs. CRS' local partners will likely remain leaders in HIV care for children by providing comprehensive care and treatment in settings that ensure access to high-quality HIV care.

CRS would like to thank its partners who participated in this analysis. Their commentary allowed a rich analysis of the work that is being done in partnership with CRS and will help CRS to build upon its strengths and better serve children in the future.

ABBREVIATIONS

AIDS: Acquired Immune Deficiency Syndrome

ANC: Antenatal Care

ART: Antiretroviral Therapy

ARVs: Antiretroviral

CLHIV: Children Living with HIV

CMMB: Catholic Medical Mission Board

CRS: Catholic Relief Services

DBS: Dry Blood Spot testing

DNA PCR: DNA Polymerase Chain Reaction (EID for HIV)

EID: Early Infant Diagnosis

ELISA: Enzyme-Linked Immunosorbent Assay

GECHAAN: Gembu Center for HIV and AIDS in Nigeria

GFATM: Global Fund to Fight AIDS, Tuberculosis and Malaria

HIV: Human Immunodeficiency Virus

IATT: Interagency Task Team on Prevention of HIV in Pregnant Women, Mothers and their Children

IGA: Income Generating Activities

IHV: Institute of Human Virology at the University of Maryland School of Medicine

IMA: Interchurch Medical Assistance

MCH: Maternal Child Health

OVC: Orphans and Vulnerable Children

PLHIV: Persons Living with HIV

PMTCT: Prevention of Mother-to-Child Transmission

SCMS: Supply Chain Management System

SILC: Savings and Internal Lending Communities

SOB: Shortness of Breath

U.N.: United Nations

UNAIDS: Joint United Nations Programme on HIV/AIDS

VCT: Voluntary Counseling and Testing

WHO: World Health Organization

BACKGROUND

Catholic Relief Services has HIV and AIDS programming in over 60 countries and serves 8 million people who are infected and/or affected by HIV. In various ways, CRS reaches children infected and affected by HIV, including by providing care and treatment to children living with HIV (CLHIV). CRS is at the forefront of HIV care and support in resource-limited countries, providing support in rural and urban settings to poor and marginalized families who require services related to HIV. Many of the Catholic hospitals that are linked to CRS' response to the HIV pandemic have provided care and treatment to people living with HIV for over 20 years. This analysis will focus specifically on CRS' programs that are providing care and treatment to CLHIV.

EPIDEMIOLOGY OF PERINATAL HIV INFECTIONS



Exploring health needs of young HIV patients requires an appreciation for the magnitude of the HIV pandemic. Photo: David Snyder for CRS

Presently, over 2 million children are living with HIV due to vertical transmission (mother-to-child transmission) of this infection.¹ Approximately 400,000 children were newly infected with HIV in 2009, while 275,000 died secondary to complications related to HIV.² As a result, the number of children requiring treatment and support for HIV infections increases annually. Perinatal HIV is particularly challenging in areas such as sub-Saharan Africa that have a high prevalence of HIV.

Mortality rates in children due to perinatally acquired HIV are particularly high, and in many countries, perinatal HIV and associated complications are the leading causes of death in children under five years of age. In many instances, children die before the diagnosis of HIV is confirmed. Access to diagnostic tools, such as HIV DNA PCR, that facilitate diagnosis of HIV in infants as early as six weeks of age, is lacking in many countries. This is especially true for countries with a high prevalence of HIV. In such settings, nearly half of CLHIV die prior to their second birthday.³ These deaths are largely preventable with access to early treatment interventions designed specifically for young children. Through the support of programs such as the President's Emergency Plan for AIDS Relief (PEPFAR), the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) and the work of various philanthropic, government and nongovernment responses, infants infected with HIV are now identified within the first three months of life. Early infant diagnosis (EID) using highly sensitive diagnostic techniques means that CLHIV can begin lifesaving medications at an early age and thus improve chances for long-term survival.

The diagnosis and treatment of children remains complex due to several barriers. These barriers are beginning to be overcome as a result of lifesaving programs, but many obstacles still exist.⁴ Pregnant women are often unaware of their HIV status because they do not present themselves for antenatal care. HIV counseling and testing are critical interventions for women at risk who are pregnant or lactating. As of 2009, fewer than half of pregnant women receive HIV counseling and testing.⁵ Mothers who are HIV positive but are not diagnosed and therefore do not receive HIV treatment during their pregnancies are at an increased risk of passing the disease to their children prenatally or during labor and delivery. Second, children are also at risk of contracting HIV from breast milk. Due to a lack of access to clean water and the expense of infant formula, exclusive breastfeeding is often the best nutritional option for infants born to mothers living with HIV. HIV-positive mothers who receive antiretroviral therapy (ART) during lactation are much less likely to transmit HIV through breast milk than those who are untreated.⁶

1 UNAIDS and WHO (2010).

2 Ibid.

3 Newell et al. (2004).

4 Shah (2007).

5 WHO and UNICEF (2010).

6 Peltier, Ndayisaba and Lepage (2009).

Until recently, pediatric formulations of lifesaving ART were not widely available in developing countries. Today, increasing numbers of children living with HIV receive these lifesaving medications. Overall, four million adults and children received ART in 2009, which represents a tenfold increase in the number of PLHIV in middle- and low-income countries who received ART since 2003. In Zambia, for example, nearly 50% of CLHIV have begun ART. This represents a two-fold increase in the last five years.⁷ Prophylaxis against opportunistic infections is an equally important intervention for CLHIV. Early treatment that included once-daily cotrimoxazole prophylaxis significantly reduced mortality among HIV-infected children, and its use is consistent with the recommended standard of care.⁸ While this is a great improvement, there are still major gaps in coverage.⁹

7 Republic of Zambia (2008).

8 WHO (2009).

9 Ibid

CLINICAL INTERVENTIONS TO REDUCE MOTHER-TO- CHILD TRANSMISSION OF HIV



*Evidence of the successful pediatric ART program is demonstrated by the health of infected children and the strength and resolve of their parents and caregivers.
Photo: Karen Kasmauski for CRS.*

The Joint United Nations Programme on HIV/AIDS (UNAIDS) has developed a framework for reducing mother-to-child HIV transmission by identifying strategic activities, four of which specifically refer to health systems for children.¹⁰ With these strategies in mind, children are gaining more attention from international aid organizations, local governments and the donor community.

Antiretroviral prophylaxis has had a positive impact on mother-to-child transmission of HIV. The World Health Organization (WHO) recently modified the guidelines for infant feeding and the prevention of mother-to-child transmission (PMTCT).¹¹ These changes reflect a plan to expand the use of antiretrovirals (ARVs), both for treatment of pregnant HIV-positive mothers and as prophylaxis to prevent vertical transmission of HIV. These modifications will improve outcomes for infants born to women infected with HIV.

The Interagency Task Team (IATT) on Prevention of HIV in Pregnant Women, Mothers and their Children set a goal of enrolling 80% of HIV-positive pregnant women in PMTCT programs to ensure long-term care and support.¹² Currently, data indicates that the proportion of women who are tested for HIV during pregnancy is increasing. Twenty-six percent of pregnant women in low- and middle-income countries received at least one HIV test in 2009. This represents a threefold increase in the past five years.¹³ Progress has been convincingly documented; however, many challenges remain due to wide variations in access to HIV testing and PMTCT services within these countries. HIV prevention services for women are not monitored consistently across programs; thus, it is difficult to make comparative assessments across all HIV prevention programs.

WHO endorses an approach to PMTCT of HIV that includes the following:

- Prevention of HIV in women and men of reproductive age
- Prevention of mother-to-child transmission of HIV during pregnancy and breastfeeding
- Treatment, care and support of women living with HIV, their children and their families

Implementation of this approach can reduce perinatal transmission of HIV from 35% to a rate as low as 2%.¹⁴ By providing ARV prophylaxis to HIV-positive pregnant women, over 200,000 new infant HIV infections have been averted in the past seven years.¹⁵

10 WHO (2010c).

11 WHO (2010b).

12 WHO and UNICEF (2010).

13 Ibid.

14 WHO (2010c).

15 K4Health (2010).

Largely through PEPFAR funding, CRS has provided care and treatment to families living in Africa and in the Caribbean regions. CRS leads the five-member consortium AIDSRelief, which is funded by PEPFAR.¹⁶ Of the 209,537 patients currently receiving ART through CRS' AIDSRelief program, 8.65% (18,118) of the patients are children. As of September 30, 2008, PEPFAR supported lifesaving treatment for more than 3.2 million men, women and children worldwide. Of those who received PEPFAR-supported treatment, the percentage of those who were children rose from 3% in fiscal year 2004 to 8% in fiscal year 2010. In countries receiving Emergency Plan care and treatment funds, a benchmark has been set so that 10% of the plan's enrollees should be children under the age of 15 years. As a PEPFAR recipient, CRS has been working toward this goal, along with other implementing partners in PEPFAR countries. The table below illustrates AIDSRelief's current pediatric enrollment by number and percentage.

Table 1: AIDSRelief Pediatric Enrollment, by Country

AIDSRelief Country Program	# of Pediatric Patients on ART 8/31/2010	% of Patients on ART 8/31/2010¹⁸	Estimated CLHIV¹⁹
Ethiopia**	132	17.56%	73,000
Guyana	73	7.27%	_20
Haiti	176	6.02%	12,000
Kenya	6,084	11.43%	180,000
Nigeria	2,573	5.42%	360,000
Rwanda	59	14.34%	22,000
Tanzania	2,850	7.72%	160,000
Uganda	2,835	8.68%	150,000
Zambia	3,336	7.24%	120,000
TOTAL	16,096	8.36%	1,077,000

¹⁶ AIDSRelief partners include the following: CRS, University of Maryland's Institute of Human Virology, Futures Group International, Catholic Medical Mission Board and Inter-church Medical Assistance.

¹⁸ These percentages are calculated based on the number of pediatric ART patients within the total population of ART patients who are treated by AIDSRelief.

¹⁹ UNAIDS (2009).

²⁰ This data is not available for Guyana.

DESCRIPTION OF PROGRAM ANALYSIS



Comfort and care for children with HIV must begin with a comprehensive facility-based care plan, which includes a multi-disciplinary team of skilled nurses, physicians, and trained community health workers. Photo: Sean Sprague for CRS

This evaluation sought information about care and treatment of children, as well as infants, whose mothers were enrolled in PMTCT programs. Many of CRS' local partners have both AIDSRelief and PMTCT programs; thus, these partners have the opportunity to link adult, obstetric and perinatal care. While CRS has strengthened its capacity to treat children, each country has experienced unique challenges, and local partners have important lessons to share with others who seek to scale-up services for children with HIV.

Many children and their families need psychosocial support as they address the emotional and cultural challenges that they encounter. The assessment analyzed the current status of psychosocial support for children. Specific issues that concern disclosure, stigma and discrimination were also investigated.

Basic needs that pertain to health and wellness were also assessed. The analysis explored access to general health services for CLHIV and for their family members. Access to nutritious foods was reviewed because it pertains to infant feeding, and child and adolescent nutrition.

Innovations in care are important components of HIV care through CRS. The assessment examined new approaches to care of children and youth, and it looked critically at the system of health care delivery. The assessment analyzed the manner in which staff develop and refine their skills, while also determining how CRS' programs support staff's personal and emotional needs.

This document will present the overall findings of this assessment and provide recommendations for the replication and scale-up of other programs for CLHIV.

METHODS



Caregivers find ways to support children to remain adherent to HIV treatment regimens. Photo: David Snyder for CRS

A consultant was hired to interview selected programs in which CLHIV are served by CRS. A questionnaire was developed as a template for the interviews by the CRS HIV Unit and the consultant. (The questionnaire is available in the appendix.) An e-mail was sent out to the AIDSRelief's Chiefs of Party as well as to the CRS HIV electronic mailing list to solicit participants for the analysis. AIDSRelief chiefs of party were asked to identify one to three local partners who had pediatric care and treatment programs with significant pediatric enrollment (5% or more) to participate in the interview. Other CRS programs providing care to CLHIV were asked to identify local partners as well. CRS provided the consultant with the contact information for the participating partners, and the consultant coordinated a time to carry out the interview by phone. When possible, partners were provided with the interview template prior to the interview in order to formulate ideas. If the partner was unable to review the template prior to the interview, the partner was still able to participate. The interview required no quantitative information or data. Country programs provided the interviewer with some general overall program data to help provide an overview of the local partners' programs. Each interview was scheduled to last approximately one hour. The interviewer called each of the local partners on the designated number, and CRS absorbed the full cost of each call. There was no requirement or incentive for participation.

The table on the following page illustrates each of the programs that participated in the assessment. The table includes the name of the project, its source of funding and its pediatric enrollment at the time of the interview.

Twenty-four programs were selected for this evaluation. Each program was contacted via e-mail, and a follow-up telephone call was made to schedule a telephone interview with ART program leaders. All 24 programs agreed to participate in the interview; however, five programs were not included in the results due to their failure to complete the interview. The consultant made at least four attempts to complete the interview.

The table on the following page indicates the name and title of the person from each program who participated in the interview. Seven of the ten AIDSRelief country programs participated in the analysis. One non-AIDSRelief program participated (Nouvelle Esperance in Burundi). A total of 19 interviews were carried out with 19 local partners in seven countries.

Table 2: Programs that Participated in the CLHIV Interview

Name of Hospital/ Program	Country	Source of Funding	Number of Children on ART (and % of total enrollment) as of 8/31/2009
Nouvelle Esperance	Burundi	CRS, World Bank, private donors, government	(NA) ²¹
Hospital Sacre Cœur Milot	Haiti	AIDSRelief	45 (6.47%)
Hospital St. Boniface	Haiti	AIDSRelief	29 (12.10%)
Kendu Adventist Hospital	Kenya	AIDSRelief	206 (8.67%)
St. Monica's Hospital	Kenya	AIDSRelief	136 (10.11%)
Mombasa CBHC (Mikindani Clinic)	Kenya	AIDSRelief	134 (13.81%)
Gembu Center for HIV and AIDS in Nigeria (GECHAAN)	Nigeria	AIDSRelief	46 (8.90%)
Bishop Murray Hospital	Nigeria	AIDSRelief	108 (6.97%)
Al Noury Hospital	Nigeria	AIDSRelief	107 (11.50%)
CS Bungwe	Rwanda	AIDSRelief	53 (11.47%)
Bombo	Tanzania	AIDSRelief	326 (11.00%)
Muheza	Tanzania	AIDSRelief	238 (10.72%)
Lacor Hospital	Uganda	AIDSRelief	291 (12.37%)
Nsambya Hospital	Uganda	AIDSRelief	247 (9.35%)
Virika Hospital	Uganda	AIDSRelief	213 (11.17%)
Macha Mission Hospital	Zambia	AIDSRelief	160 (9.20%)
Mtendere Mission Hospital	Zambia	AIDSRelief	109 (7.20%)
Malcolm Watson Hospital	Zambia	AIDSRelief	121 (8.32%)

²¹We did not receive information about the total enrollment.

RESULTS/ANALYSIS



Successful clinical interventions demand a family-centered approach that will meet the needs of women and their children. Photo: Laura Sheahan/CRS

Common themes have been identified as a result of this assessment. This section will explore these themes in a few specific categories: *strengths*, *challenges* and *recommendations*. Specific examples are highlighted throughout this section to explain how programming is implemented in the context of each featured intervention. Though programmatic components vary, this analysis revealed that most programs experience similar challenges and have common concerns. Similarly, common strengths were identified. Examples of practices that were used at the local level are highlighted throughout this section as *local practices*.

STRENGTHS

Access to Drug Pipeline

Programs reported consistent, uninterrupted access to antiretroviral drugs and prophylactic drugs via their respective, designated pipelines. Over the past several years, specific pediatric formulations have become more available, although in many cases, pediatric formulations are more expensive than adult antiretroviral drugs. The Gembu Center for HIV and AIDS in Nigeria (GECHAAN) pointed out that they are receiving sufficient quantities of all drugs; however, they would like to receive more pediatric formulations. Programs in Rwanda and Zambia have access to a government pipeline, which is assessed as a sustainable mechanism for continued access, according to the programs surveyed. Government pipelines illustrate a commitment to continued access and the continued development of the infrastructure necessary to sustain access to ARVs.

In 2005, PEPFAR established the Supply Chain Management System (SCMS). The purpose of SCMS is to ensure the integrity of the antiretroviral pipeline so that patients have uninterrupted access to treatment.²² SCMS is working with donors and local governments to establish a secure pipeline based on local contexts.

Family-Centered Care

Each program expressed great pride in its ability to provide family-centered care. According to local partners, identification of HIV-positive children is challenging, so establishing a family-centered approach is integral. There are several ways that these programs achieve a family-centered approach.

1) *HIV testing in antenatal care*: All women who present themselves for ANC are offered HIV testing. This intervention is widely accepted by pregnant women due to their desire to have healthy babies. Practitioners follow up with additional treatment for women who are identified as HIV positive. This greatly decreases the chances of mother-to-child infection. *Local practice*: At Mtendere Hospital in

22 PEPFAR (2009).

Zambia, all mothers are offered testing at the ANC. If they test positive, they are immediately enrolled in the ART program. Children are given Dry Blood Spot (DBS) testing at five weeks and five months and are monitored by the ART program.

2) Eighteen-month follow-up period for infants born to HIV-infected women: Once a baby is born to an infected mother, the baby is enrolled in pediatric ART and tested through 18 months.²³ Many programs have recently acquired DBS testing technology or access to DBS at another location. This is a significant improvement to ELISA testing for infants since maternal antibodies produce a possible false-positive result. DBS tests for the genetic material of the actual virus; therefore, this test can indicate an infant's serostatus prior to 18 months (when maternal antibodies are no longer present). Local practice: (1) For patients at Bishop Murray Hospital in Nigeria, DBS technology is only available at a laboratory center located 300 kilometers away. This testing is done for children in their program at six weeks of age. As a result, mothers must travel long distances to get their children tested. (2) At Virika Hospital in Uganda, DBS technology is being used to follow up with children at home. Children who test negative are followed for one full year after the mother stops breastfeeding.

3) Family voluntary counseling and testing: Clinics are training staff to encourage the rest of the family to come in for testing when one member of the family tests positive. There are a variety of entry points for family VCT. For example, when a woman tests positive through ANC, she is encouraged to bring in the whole family for testing. Similarly, when a man tests positive, he is encouraged to bring the family to the clinic or hospital. Staff is trained to counsel the family to encourage this process. Local practice: At Kendu Adventist Hospital in Kenya, family enrollment forms are used to track children of an HIV-infected parent and their families. The parent is asked how many children they have and whether the children have been tested. The parent is then encouraged to bring in untested children for testing. This process is tracked using the family enrollment form.

4) Community mobilization for VCT: Programs are sending counselors, staff and volunteers into the community to educate people about HIV and to offer testing on the spot. These programs encourage testing for the whole family. Local practice: At the Gembu Center for HIV and AIDS in Nigeria (GECHAAN), "Outreach VCT" is done on a weekly basis. GECHAAN reports that it administers approximately 500 tests per week using rapid testing in the community.

The family-centered approach is very successful, and six of the programs that were assessed (31.6%) identified the family-centered approach as "the most unique and successful part of their program." There are a few challenges that do not lessen the family-centered approach's success but rather draw our attention to the need for creative thinking and teamwork by program staff.

Local practice: At Mombasa CBHC in Kenya, the clinician and nurse see clients in satellite clinics as needed, in order to improve access to follow-up care.

²³ At least two HIV tests are conducted in the first 6 months of life. If the tests are negative, a third test is obtained before 18 months of age.

(Mikindani Clinic is an example of one such clinic.) Clinical officers are also rotated through these satellite clinics, which are set up in rural areas to see clients at the community level, closer to home. Volunteers visit clients at home and identify needs. Information gathered during home visits is shared with nurses and clinicians.

Prevention of Mother-to-Child Transmission

Though discussed above in the section about the family-centered approach, PMTCT is worth addressing separately. Fifteen of the programs explained during interviews that the focus on PMTCT has greatly assisted their ability to prevent infections in children. They reported that PMTCT also provided the opportunity for early intervention for HIV-positive babies. Most programs pointed out that more resources for PMTCT would greatly enhance their pediatric ART program. Having the ability to provide women with lifesaving therapy in one of two ways (long-term antiretroviral therapy or treatment during pregnancy/delivery) markedly reduces the risk of passing the virus to the child. PMTCT programs have also allowed health care providers to follow infants for the first 18 months of life.

Technical Assistance and Training

Programs reported that the technical assistance provided by AIDSRelief, specifically the clinical mentoring and didactic training provided by the Institute of Human Virology (IHV), is strong. The training takes place in a variety of ways:

- 1) *On-site mentoring*: AIDSRelief staff comes to the hospital/clinic to provide on-site mentoring to clinical staff (doctors, nurses, clinical associates/officers, counselors). This type of mentoring is largely provided by IHV. Futures Group, the consortium partner for monitoring and evaluation and strategic information, provides mentoring to the hospital's strategic information officers. CRS supports training for a variety of program staff in areas of program management. Ten programs provided positive feedback regarding clinical mentoring. Specific pediatric training has also been provided with this methodology.
- 2) *Training*: Program staff attends government-sponsored and CRS/AIDSRelief-sponsored training sessions in a variety of clinical areas (e.g., pediatric care and treatment). Donor-sponsored trainings are conducted in accordance with government treatment guidelines.
- 3) *"Refresher courses"*: AIDSRelief, independently and in conjunction with local ministries of health, provides refresher courses to clinical staff.
- 4) *Clinical case conferences*: AIDSRelief staff and program staff discuss individual patient cases and conduct discussions on how to handle the cases. Interviewees did not express the need for more training or support in pediatric care and treatment.

Adherence and Treatment Support

Most respondents spoke in great detail about their adherence programs. Before starting ART, all programs enroll pediatric patients and their caregivers in intensive treatment preparation programs. As part of this program, the caregiver is educated on how to administer medications or assist the child in taking the medication (based on the child's age). In many cases, the child is given an adherence "trial" in order to prepare the child to take medications exactly as prescribed. During this trial period, the child begins cotrimoxazole, a medication that is commonly used to prevent certain opportunistic infections. Program staff monitor the child's ability to remain adherent to the cotrimoxazole, as an indicator of adherence to ART. Other adherence techniques such as pill counts, adherence calculations, regular clinic visits, regular visits with counselors and home visits when there are problems/concerns were all mentioned several times. Programs report adequate support and staff training in this area.

Local practice: At Bishop Murray Hospital in Nigeria, the designated caregiver (identified by the family) is trained in three modules: preparation, strategies on dispensing medications and adherence. Adherence is monitored through home-based care. The team responsible for home-based care includes clinicians and volunteers as well as a spiritual leader. If problems are identified at the community level, more extensive follow-up is done with the child.

Programs also carry out unique interventions to help children stay physically and emotionally "well." *Local practice: At Nsambya Hospital in Uganda, a peer group has been established called Unique Sisters. This adolescent group uses song, dance and drama to promote healing. Additionally, there are monthly pediatric counseling sessions.*

Several programs expressed a need for more funds to hire the necessary staff not only to facilitate support groups to do this job but also to do home visits when needed. Some programs were not able to carry out any home visits and relied only on volunteers. The expanse that the catchment areas programs cover also proves to be a challenge when following patients in the community.

Clinical Program Evaluation

All interviewees reported that their clinical programs and IHV consistently gave each other feedback. Respondents spoke of regular (annual or twice yearly) clinical program evaluations that are carried out by IHV. Program evaluations provide recommendations to clinical staff, who can then use these recommendations to improve programs.

CHALLENGES

Obstacles to the Family-Centered Model of Care

Common challenges include the following:

1) *Lack of involvement*: Women are often willing to get tested, but men are resistant to coming in for testing. Two programs identified as a priority the goal of increasing the participation of men in testing and support groups.

2) *Vulnerability of women*: When women disclose their HIV-positive status to their husbands, they are at risk for violence or abandonment by their husbands. Two programs are prioritizing the safety and well-being of women in these situations by focusing on education and by counseling women and men.

3) *Access to clinic/hospital*: Families are often living far from clinics in remote areas. It is challenging for families to get to the clinic, and it becomes even more challenging when multiple members of the family need to get there. Some programs are focusing on setting up satellite clinics to reach those living in hard-to-reach areas

Sustainability

All respondents reported uncertainty about the future of their programs if AIDSRelief is no longer able to provide funding. Some countries have greater confidence in the local government's ability to take over; however, most local partners had little knowledge of how programs would be handled in the absence of Emergency Plan funding. Most interviewees had not participated in extensive discussions on this topic. Most programs are only receiving funding from AIDSRelief for HIV care and treatment. This funding is often the largest and/or the only source of donations coming into the programs' clinics and hospitals. The absence of this funding would be a major threat to human resources and other clinical tools that are obtained through this program.

On December 1, 2009, U.S. officials announced a new five-year plan to refocus their response to the international HIV crisis and to emphasize long-term, sustainable improvements in prevention, treatment and care.²⁴ This plan speaks specifically to the transition from emergency response to a sustainable response with greater capacity building of governments and local management of Emergency Plan efforts.

Access to Community Services and Wrap-Around Services

Programs expressed confidence in their ability to care for and treat children with available resources. The area in which programs expressed the most concern was related to community services and wrap-around services to complement the work being done clinically. A lack of funding is the underlying cause of the primary challenge facing these programs. Financial resources support care and treatment, but the funds rarely support wrap-around services such as safety net programs (nutrition, shelter and child protection). Many respondents expressed a need for these community services, as indicated by their comments in the following section.

24 PEPFAR (2009).

1) *Orphans and vulnerable children (OVC)*: Many programs are not receiving separate funding to support OVC. Some programs receive OVC funding through CRS, and they use these funds to support OVC by building family-centered support services to improve food security, to enhance child protection and to expand access to educational opportunities for OVC. Other programs work with various community organizations that receive separate funding to care for OVC. Regardless of the network established to link pediatric ART programs to wrap-around support services, staff interviewed for this study identified large gaps between the resources available and those resources needed by CLHIV. Education and adequate nutrition are the greatest needs for children who were identified by these programs. The need for food undermines the success of ART programs since children cannot be fully successful in therapy without good nutrition. Several program directors who were interviewed stated that they or their program staff often gave individual children or families money from their own pockets for food or other necessities. St. Boniface Hospital in Haiti identified a need for food, education and overall basic assistance for children. Sacre Coeur Hospital in Haiti would like to see the establishment of a support system for mothers and their children. Virika Hospital in Uganda identified that the greatest needs of their program are nutritional support and educational support for children.

2) *Pediatric counseling and support groups*: Programs often do not have enough resources to offer consistent counseling to all children. Programs would like to have support groups for children at various ages (children younger than five years old, children 6-11 years old, children 12 and above). Bungwe Health Center in Rwanda offers three pediatric support groups to cover children of all ages. A counselor also provides support to parents through counseling sessions. Six programs reported the need for pediatric support groups but did not have the funding to run them. Two programs reported that they are running groups informally for children but do not have the funds to support them. At St. Boniface Hospital in Haiti, a “peer-to-peer” support group has been established. This group is not funded, but the hospital has moved forward with it based on need. Virika Hospital in Uganda would like to establish support groups and has identified this as a top priority for the program. Bishop Murray Hospital in Nigeria is running an informal pediatric support group that is not currently funded. The hospital is seeking funds for this type of activity through faith-based groups and the church.

3) *Disclosure*: St. Monica’s Hospital in Kenya and Macha Mission Hospital in Zambia highlighted the importance of comprehensive counseling about disclosure and specific “disclosure strategies.” Often programs do not have the staff to provide sufficient counseling. St. Monica’s pointed out that counseling is needed for the adults and the children. Adults often face feelings of extreme guilt and fear their children will judge them. Macha identified as key issues staffing and the need to expand counseling for disclosure into the community. Additionally, staff would like to be able to offer more regular support groups on this issue.

4) *Food security*: All programs reported food insecurity in their catchment areas. Programs would benefit from the ability to refer families to other NGOs or to community programs that receive funds for food security programming.

5) *Poverty alleviation/SILC*: Several programs expressed interest in income generating activities for families and children in their programs. Many of those interviewed were knowledgeable about IGAs but lacked referral sources for program participants.

6) *Home visits*: Many programs have integrated home visits into their ART programs for those patients who are having adherence problems—those who are not showing up for appointments or who are ill or vulnerable in other ways. The strength of this component of the program is limited by human resources. Many programs have successfully integrated the use of community volunteers into this component of their programs. Of course, challenges remain in training and retaining community volunteers as well as in ensuring their availability and ability to carry out all of the work needed.

Infant Feeding Options

Due to poverty, mothers do not have varied options for feeding their infants. Infant formula is expensive or unavailable, and there is no steady supply of clean water. Therefore, mothers must breastfeed their children. The risk of mother-to-child HIV transmission is reduced if exclusive breastfeeding is limited to the first six months of a newborn's life, but a small, measurable risk will persist until breastfeeding is discontinued. St. Monica's Hospital in Kenya would like to be able to offer mothers other feeding options and more education on infant feeding. Additionally, nutrition for mothers is a big issue. The hospital pointed out that mothers often do not have sufficient nutrition for themselves. In addition, mothers do not have the resources to offer appropriate foods to their children at six months of age.

Poverty

All of the communities that are served by the partners that were interviewed are riddled with extreme poverty. Poverty is often seen as an underlying cause of HIV transmission. As long as poverty exists in these communities, HIV is a threat. Local partners' successes are evidence of their efforts to promote prevention, care and treatment; however, poverty is a limiting factor for all of the programs. Bungwe Health Center in Rwanda pointed out that poverty is responsible for nonadherence to HIV treatment (ART) in children, because children living in poverty are poorly nourished. Undernutrition often causes children to be unable to tolerate antiretroviral medication.

RECOMMENDATIONS

1) HIV counseling and testing must be made available in the home setting as a component of home-based care. Using this approach, HIV counseling and

testing can be widely available to all family members, including the children. HIV education should be developmentally appropriate, and specific HIV-awareness programs should address the needs of men as well as women. Stigma and stress related to HIV can also be addressed in the family setting. Satellite clinics, similar to those established by Kenya's Mikindani Clinic of Mombasa Hospital, can be identified and incorporated into the clinical networks where care is currently difficult to access.

2) Broad-based collaborations between AIDSRelief, its local partners and local governments are needed for future success. Sustainable programming for pediatric ART will be strengthened when partnerships include the full spectrum of stakeholders.

3) Work at the local level should be expanded to include important safety net programs (nutrition, shelter and child protection, for example), to support the donors' expectations for a comprehensive response to CLHIV. AIDSRelief will need to provide capacity building for local partners to include pediatric ART as a component of a holistic approach to PLHIV. In this regard, pediatric ART must be integrated into community-based, family-centered care. Community caregivers need to be trained and informed to participate in this approach and to ensure high-quality comprehensive care.

4) CRS must encourage its local partners to diversify their funding by seeking grants for wrap-around services. Such services include pediatric counseling, food and nutrition supplements and economic strengthening. The additional services will enhance the quality of the response to pediatric HIV.

5) CRS and its local partners must develop a referral guide for clinical staff and for community outreach workers. This guide should enhance access to support services that are available to families with children infected with HIV.

6) Advocacy at the local, regional, and country level is essential in order to ensure continued financial support for CLHIV. The advocacy efforts should be targeted to improve access to high-quality ART for children and universal access to early infant diagnostic tools for HIV-exposed infants. Advocacy for a family-centered approach should also address HIV prevention for couples, particularly for couples that are planning to have children.

7) All programs that provide pediatric ART should seek future funding from a variety of sources, including international aid agencies, private foundations and faith-based institutions. When funding is not available for wrap-around services, partnerships with other community programs, such as those directed by the Church, may provide opportunities to secure the additional services.

8) Programs that do not have volunteer components may consider integrating community volunteers into their programs. Not only does this help achieve program goals but also it decreases stigma in the community and creates potentially rewarding opportunities for community members.

CONCLUSIONS



While pediatric ART requires a lifelong effort, the pride in positive short-term gains can motivate families and communities to prepare for a child's future.
Photo: Sean Sprague for CRS

Catholic Relief Services provides comprehensive HIV treatment and support services for children. These services include high-quality, durable ART and close clinical monitoring for early detection of both clinical and virological responses to treatment. This ensures excellent health outcomes for children living with HIV. CRS' local partners have successfully operationalized effective pediatric HIV care and treatment. Impressive successes have also been made in the prevention of mother-to-child HIV transmission and in the early identification of HIV infections during the newborn period.

This evaluation also demonstrates that CRS' local partners provide comprehensive community-based support through home-based support and community outreach. Adherence support and family-centered HIV awareness are evident. Family-centered care and treatment is a challenge, but this approach has become a central component of AIDSRelief's pediatric ART programs.

Sustainable programming will become the cornerstone of CRS' work with children living with HIV. Close collaboration with local partners to secure a sustainable platform of services in pediatric ART means that CRS and its partners will be able to provide high-quality, comprehensive care for CLHIV. There is still a great need for the scale-up of pediatric programs. More funding will be critical to realize this important goal. CRS' pediatric ART programs will serve as positive models of care, and such models are likely to be replicated and expanded in the future.

APPENDIX: INTERVIEW GUIDE



Staff are trained to treat and support children and adults through a family-centered approach to ART. Photo: Karen Kasmauski for CRS.

Interview Guide for Program Assessment: Children Living with HIV

Background Information	
Country	
Date of interview	
Interviewee	Name: Position: Contact information:
HIV situation	Prevalence rate: Generalized or concentrated epidemic? (If focused, where?): Number or percentage of children living with HIV in country (approx. is fine): At which level (government, donor, civil society, community) is the response strongest and weakest?
Name of project	
Location of project (geographic scope in country)	
Length/size of project	Runs from _____ to _____ Grant amount: Related proposals submitted or awaiting results (please list): Is funding specifically to support the care and treatment of children, or does funding support family-centered care?
Current/existing donor(s) (List donors)	
Implementing partner(s)	
Project Description	
In what year did you begin to provide general care for children living with HIV?	
If you provide drug treatment (ART) for children, in what year did you begin this service?	
Does your program include adherence support for children?	If yes, describe how this takes place.
Does your program include disclosure support groups for children with HIV and their families?	If yes, please describe.
Does your program include any other support groups for children?	If yes, please describe.

Where does your program provide care and treatment services for children? Please check all that apply.	<input type="checkbox"/> 1. church <input type="checkbox"/> 2. clinic <input type="checkbox"/> 3. home <input type="checkbox"/> 4. community center <input type="checkbox"/> 5. school <input type="checkbox"/> 6. other (specify) _____ _____
Caregivers and Clinical Support Staff	
Who are the primary caregivers for children? (Check all that apply.)	<input type="checkbox"/> 1. mothers <input type="checkbox"/> 2. fathers <input type="checkbox"/> 3. grandparents <input type="checkbox"/> 4. aunts and uncles <input type="checkbox"/> 5. neighbors <input type="checkbox"/> 6. older siblings (ages?) <input type="checkbox"/> 7. community volunteers <input type="checkbox"/> 8. local welfare officials
How are caregivers trained to provide care to children with HIV?	
Who provides clinical HIV care to children?	Identify all that apply. <input type="checkbox"/> 1. doctors <input type="checkbox"/> 2. clinical associates <input type="checkbox"/> 3. nurses <input type="checkbox"/> 4. community health workers <input type="checkbox"/> 5. other (please describe):
How are these providers trained to care for children? Please explain.	
How do providers receive information about new advances/guidelines? Please explain.	
Please describe any continuing education plans for your providers.	
Support Materials, Training Resources, Tools	
Are you aware of any teaching strategies, support materials, training materials and/or tools that are currently in use in your country that help to facilitate HIV care for children? If yes, for what age groups? Interviewer: Please request a copy of the tools, training materials. Ask for photos.	
Referrals, Linkages, Integration	
At a macro level, does the care and treatment component link with any government—or nongovernment—programs (health-related, education, food security, nutrition, legal aid, other)?	
If so, how does this linkage occur?	
Are referral mechanisms structured formally or informally?	

Are referral mechanisms funded?	
Does your program report on # of referrals made?	
In general, would you say that your program focuses on (1) direct treatment provision or (2) referral to other existing treatment services and programs (CRS or other)?	
Please list related ministries, CBO/NGOs, etc.	
Are there active community initiatives (either CRS-supported or not) that address the needs of children living with HIV?	Please explain.
Does the care and treatment component link to any of the following: <ul style="list-style-type: none"> • Child health programs • TB programs • Food security • OVC assistance (shelter, education, etc.) • Poverty alleviation (SILC, livelihoods) • Spiritual support • PSS • Other (specify) 	
What are these programs (e.g., IMCI, EPI, MCH) and who runs them? For TB programs: Who runs the TB programs and how does the integration happen?	
Are clients on DOTS? If so, do our caregivers play a role in this? If so, who runs these programs, and how does the integration with the TB program occur?	
Does the program provide nutritional support (food aid) or supplementary feeding programs?	
If so, what types? Where does it come from (e.g., USG, WFP, local purchase)? What about other nutritional support (e.g., nutrition education, nutritional assessment and counseling)?	
Policy Issues	
Are there any government child protection policies that support the rights of, and the health and well-being of, children?	
What are those policies? Are they actively promoted? Are there any national strategies for implementing these policies? Are those strategies available for review?	
Monitoring and Evaluation	
How is the care and treatment component monitored?	
Can you list the primary indicators that are used (or send M&E plan) at both the individual level and the program level?	
Are there any specific challenges you would like to mention that relate to the M&E component of this program?	

Has the care and treatment component ever been evaluated?	If so, when, by whom, and can you share a copy of the evaluation? If not, are any evaluations planned in the next year?
Perspectives in Program Development	
What is the most unique, creative and/or impressive feature of the care and treatment program?	
How long do children remain in your program? Where are children referred when they leave your program?	
What area of the care and treatment component needs the most improvement?	
Have you seen any significant changes in your local HIV programming over the last several years that would make pediatric care and treatment services a priority? Or less of a priority?	
Future Programming	
Do you have a sustainability plan for the child care and treatment component of your program?	If yes, please describe this plan.
Please indicate all that apply to your plan for securing a sustainable program to care for children.	<input type="checkbox"/> 1. fee for service (families pay for care) <input type="checkbox"/> 2. support through the Catholic Church <input type="checkbox"/> 3. other funding (specify) <hr/> <hr/>
Do you have plans to expand your program to treat children?	If yes, please specify.
Additional Information	
Are there any other issues related to care and treatment programming that we have not already discussed but that you would like to share?	
Are there any topics that you would like to go back and talk about in more detail?	

REFERENCES

- Joint United Nations Program on HIV/AIDS, & World Health Organization. (2010). UNAIDS report on the global AIDS epidemic 2010. Geneva, Switzerland: WHO Press. Retrieved from http://www.unaids.org/documents/20101123_GlobalReport_em.pdf
- K4Health. (2010). Prevention of mother-to-child transmission. Retrieved from <http://www.k4health.org/toolkits/pmtct/preventing-unintended-pregnancies-among-hiv-positive-women>
- Newell, M. L., Coovadia, H., Cortina-Borja, M., Rollins, N., Gaillard, P., & Gabis, F. (2004). Mortality of infected and uninfected infants born to HIV-infected mothers in Africa: A pooled analysis. *Lancet*, 364, 1236–43.
- Peltier, C. A., Ndayisaba, G. F., & Lepage, P. (2009). Breastfeeding with maternal antiretroviral therapy of formula feeding to prevent HIV postnatal mother-to-child transmission in Rwanda. *AIDS*, 23, 2415–23.
- President's Emergency Plan for AIDS Relief. (2009). Pediatric treatment and care. Retrieved from <http://www.pepfar.gov/documents/organization/114229.pdf>
- Republic of Zambia. (2008). Zambia country report: Multi-sectoral AIDS response monitoring and evaluation biennial report, 2006–2007. Retrieved from http://data.unaids.org/pub/Report/2008/zambia_2008_country_progress_report_en.pdf
- Shah, I. (2007). Antiretroviral therapy. Retrieved from http://www.hivinchildren.org/Antiretroviral_therapies/art.asp
- United Nations Children's Fund (with Joint United Nations Programme on HIV/AIDS, World Health Organization, & United Nations Population Fund). (2009). Children and AIDS: Fourth stocktaking report, 2009. Geneva, Switzerland: UNICEF. Retrieved from http://www.unicef.org/publications/files/Children_and_AIDS_Fourth_Stocktaking_Report_EN_120209.pdf
- World Health Organization. (2009). Co-trimoxazole prophylaxis for HIV-exposed and HIV-infected infants and children: Practical approaches to implementation and scale up. Geneva, Switzerland: WHO Press. Retrieved from http://www.unicef.org/aids/files/CotrimoxazoleGuide_2009.pdf
- World Health Organization. (2010a). Antiretroviral drugs for treating pregnant women and preventing HIV infection in infants: Recommendations for a public health approach. Geneva, Switzerland: WHO Press. Retrieved from http://whqlibdoc.who.int/publications/2010/9789241599818_eng.pdf

World Health Organization. (2010b). Guidelines on HIV and infant feeding: Principles and recommendations for infant feeding in the context of HIV and a summary of evidence. Geneva, Switzerland: WHO Press. Retrieved from http://whqlibdoc.who.int/publications/2010/9789241599535_eng.pdf

World Health Organization. (2010c). PMTCT strategic vision 2010–2015: Preventing mother-to-child transmission of HIV to reach the UNGASS and Millennium Development Goals. Geneva, Switzerland. Retrieved from http://www.who.int/hiv/pub/mtct/strategic_vision.pdf

World Health Organization, & United Nations Children’s Fund. (2010). Toward universal access: Scaling up priority HIV/AIDS interventions in the health sector. Geneva, Switzerland: WHO Press.

Catholic Relief Services
228 West Lexington Street
Baltimore, MD 21201 USA
Tel: (410) 625-2220

crsprogramquality.org

