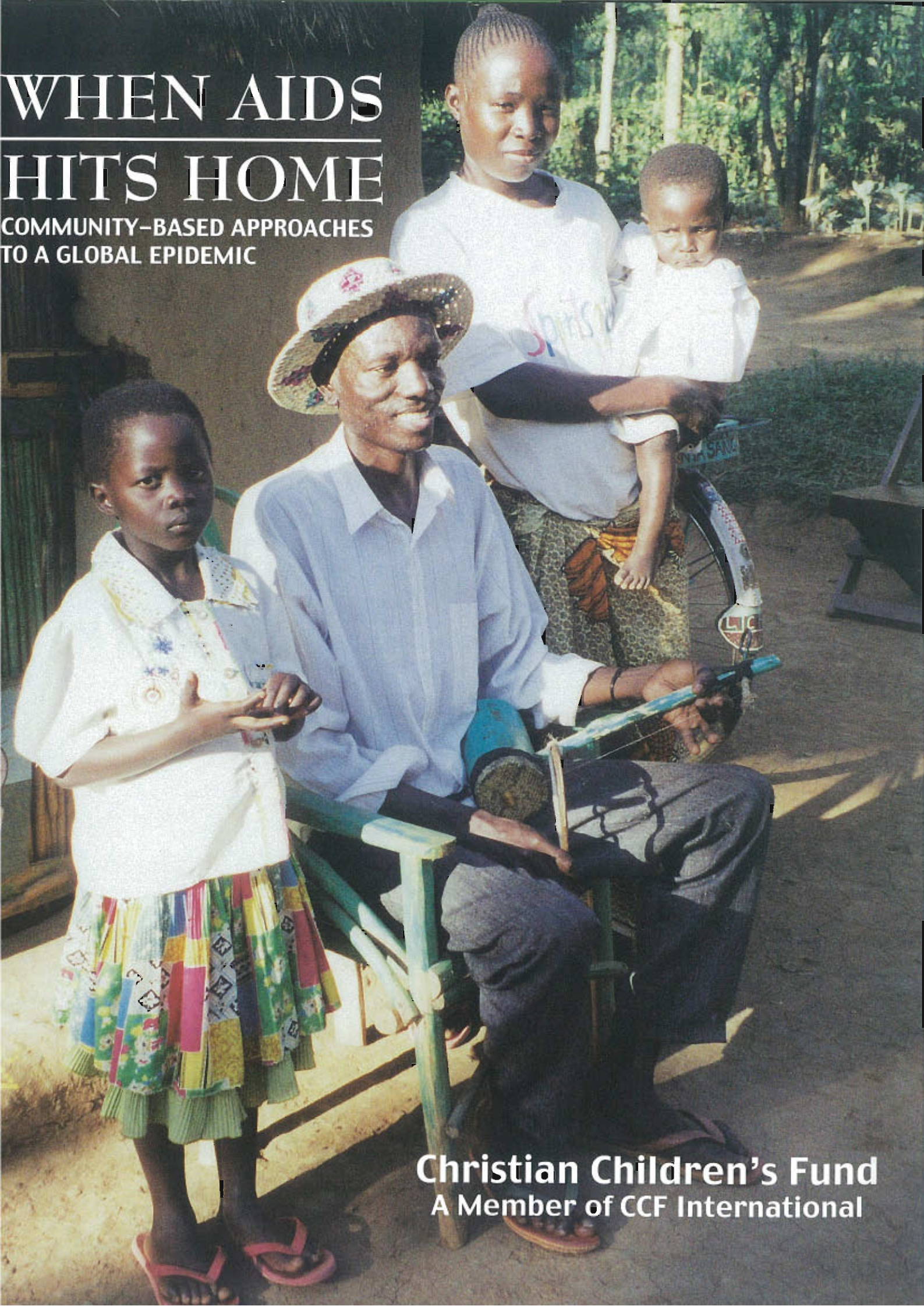


# WHEN AIDS HITS HOME

COMMUNITY-BASED APPROACHES  
TO A GLOBAL EPIDEMIC



**Christian Children's Fund**  
A Member of CCF International



# Helping Families Survive—Home-Based Care

In the developing world, people suffer through the last stages of HIV/AIDS in their own homes, with little or no medical support. Hospitals turn away patients because there are not enough beds. The cost of medical care and antiretroviral drugs remains beyond the reach of all but the most elite.

The pattern of how HIV/AIDS is spread in developing countries is all too familiar. And those who suffer the most are often the innocents, the children, left behind when both parents die of AIDS. Some men unknowingly bring the virus home to their wives, who in turn unknowingly pass it on to their children in birth. The calamity that has engulfed the family becomes apparent as the symptoms of full-blown AIDS manifest themselves. The wives care for their husbands through the last stages of the disease, and then they themselves fall ill, showing the same symptoms. At that point, the burden generally falls upon the oldest children in the family. Because their parents are often weak, children must learn how to handle everything from assisting with wound dressing and dispensing medication to cleaning the house and ensuring that younger siblings get to school.

## Home-Based Care

To help these children and their families, CCF is developing community infrastructures on which families can rely for support. In countries such as Kenya, South Africa, Thailand, Uganda, and Zambia, CCF is using a home-based care approach to help children and other family members provide for the physical and emotional needs of their loved ones.

Home-based care programs, carried out by volunteers and family members, are making a difference and reaching those in need. In Chiang Mai, Thailand, CCF's home-based care program is supporting 500 chronically ill patients, most of whom are infected with the HIV virus. In Uganda, more than 300 patients are being assisted through home-based care. The program also provides an invaluable opportunity to launch community education programs about AIDS prevention.

CCF supports its home-based care efforts by forming valuable alliances with governmental agencies as well as non-governmental and community-based organizations. In Uganda, for instance, CCF works with TASO, a preeminent AIDS support organization.



Rose's family is typical of many who received home-based care training. Rose's mother explained the changes in the home since she and her husband were trained. "Before the training, Rose's father used to speak harshly to her about having AIDS; he blamed her, shouted at her, and made her feel very bad about being infected. But in the training we learned how AIDS is transmitted and how someone with AIDS feels, their fears and their pain. My husband listened. Since that training, I have never heard him shout at her or speak an angry word. My home is happier now and he is proud of his daughter."

The CCF program not only emphasizes clinical skills, but also points out the roller coaster of emotions that someone living with HIV experiences. "Before they are trained, we have seen families so afraid to be near their sick relatives that they put food on a plate and push it over to them in a corner or even make them live in a small hut outside the house. But after training they practice good care at home. We visit and see the patient in the home, closer to the family, eating meals with them, and talking and taking part in family decisions," explained a CCF psychosocial worker.

## Building Health Care Infrastructure Through Training the Trainer

CCF works with groups like Pathfinder International's home-based care program to teach social workers how to train family members and community volunteers on care of those terminally ill because of HIV/AIDS. The social workers then go into affected communities and train an ever widening pool of community volunteers on patient care and HIV/AIDS prevention. They, in turn, bring their knowledge to affected families. This instruction focuses on basic nursing techniques, hygiene management, available pain relief, and ways to offer emotional support to patients and family members. They also teach family members how to identify opportunistic medical conditions associated with HIV/AIDS such as pneumonia and tuberculosis, so that medical treatment can be sought. Community home visitors and social workers also provide critically needed training on how caregivers can avoid contracting HIV/AIDS through their daily contact as they care for their terminally ill family members.

As part of the home-based care, CCF provides families with kits of materials that few families could afford to buy. These include first aid supplies, basic pain relief medications such as aspirin, skin ointments, plastic gloves, and wound dressings, along with basic hygiene materials.

## Mobilizing the Community

An important part of this community support is the monthly meetings during which care providers and CCF social workers come together to learn additional skills and share feelings with others in similar situations. Social workers offer coping techniques for grief, burnout, peer stigmatization, and other related problems. In addition, local health workers attend the meetings, which strengthens the ties between the clinics and the home-based care providers, and improves the referral system.

Home-based care is working. Families report better pain management, improved personal hygiene and, in general, improved well-being. In addition, participating families acknowledge greater awareness of HIV/AIDS prevention. Most of all, with CCF assistance, children who are called on to assume enormous responsibilities

## Good Practices in Home-Based Care

- Encouraging those living with AIDS to take the home-based care course enhances the individuals' ability for self care. This practice results in greater independence on the part of the AIDS-affected individual and a greater confidence in the person's ability to take care of his or her own needs where manageable.
- Providing home-based care kits to families caring for a sick relative and keeping the kits supplied gives greater autonomy to the family and increases the effectiveness of their care. The kit is replenished from the project once every three months as the need arises. In order to use resources efficiently, the family returns the kits during those times when the patient becomes healthier and does not require daily care or when the patient passes away. The kit is then given to another family caring for a bedridden patient.

are able to draw on their own resiliency and succeed.

One of the most important components of CCF's home-based care is the psychosocial support and counseling that trained social workers and community volunteers offer HIV/AIDS-affected families, especially children who are caring for their dying parents. It's this emotional and social support, coupled with other forms of assistance that helps many children manage one of the most difficult situations in life—caring for a terminally ill parent. Children are called on to show wisdom and abilities far beyond their years. Psychosocial assistance allows children to share their fears, their concerns and their problems with an adult who can offer advice and assistance.



## Holding It Together

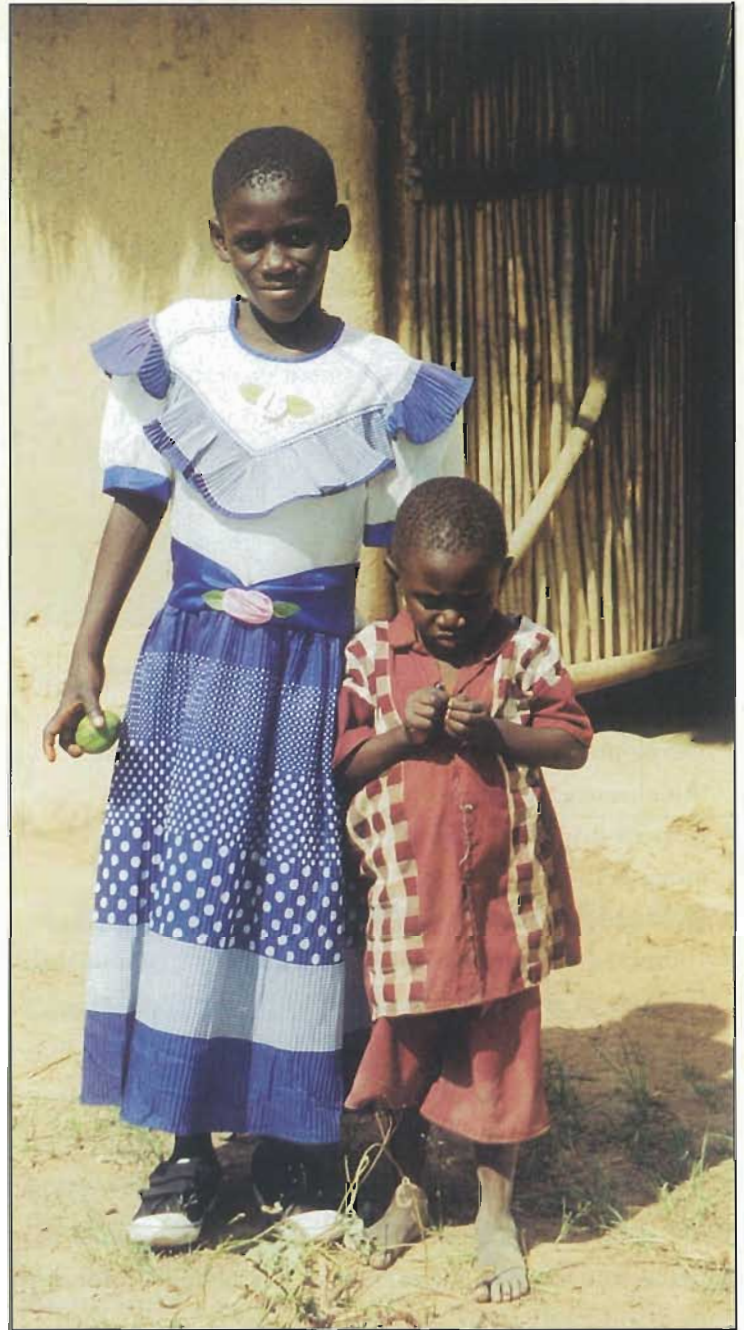
Ruth is a soft-spoken 10-year-old girl who lives in Rangala in western Kenya. Ruth's mother, Carolyn, is "down," as they say there, which literally means a person is now in the last stages of AIDS and is bedridden.

Ruth is holding her family together and seeing her mother through the last stages of her life. She is totally taking care of the house, her four-year-old brother, Philip, and her mother. When asked to describe what a typical day is like for her, Ruth sat there, and with grace and dignity and maturity much beyond her years, recounted the following:

*I woke up yesterday (which was Saturday) at 5 a.m. I swept the house. I fetched water three times. (Each trip takes about 15 minutes.) After getting the water, I prepared the porridge for the family. Then I went to the river to wash clothes. I came back and washed mother. Then prepared lunch. Mother ate a little. After lunch I went to fetch firewood. Then I brought in the clothes I had washed, and went out to look for sweet potatoes that I then prepared for dinner. After the family ate, I prepared bed for my brother and mother, then gave mother [TB] medicine.*

(On a school day, Ruth's routine is different. She prepares Philip, then takes him to the CCF daycare and gets to school herself by 7:15. Then when school is over, around early afternoon, she comes home and prepares food for her mother. Then she fetches Philip after 4:00 from the CCF center, where he has received two meals.)

For Ruth and other children like her, home-based care is making it possible for families to stay together.



## How CCF Is Helping Ruth and Others Like Her

CCF's combined approach of home-based care and psychosocial interventions is enabling families to stay together while they care for their dying loved ones at home. Home-based care teaches family members like Ruth:

- How to care for terminally ill patients properly
- How to minimize the risk of contracting AIDS as they bathe and oversee the hygiene of those who are ill

CCF's psychosocial interventions help by:

- Providing foods to supplement what is available from the home garden
- Providing a way for children and family members to express their feelings about the loss of their loved ones and their fears about what the future holds
- Helping protect the property rights for children and surviving family members like Ruth and her brother
- Assuring that children stay in school

*AIDS, Oh AIDS!*

*What animal is AIDS?*

*My uncle is gone.*

*My teacher is gone.*

*My friend is gone.*

*Who is going to buy me sweets?*

*Who is going to give me knowledge?*

*Who is going to play with me?*

*Oh AIDS, I hate you, I hate you!*

Chatula, 13 years old  
Tithandizane Village, Zambia



# Fighting A Dubious Birthright—Mother-to-Child Transmission

For some children, AIDS begins at birth. According to UNICEF, in 2001, 800,000 children under the age of 15 contracted HIV, over 90 percent of them from their mothers at birth or during breastfeeding. Many of these children die before they reach the age of five. While mother-to-child transmission remains one of the most tragic developments in the AIDS crisis, CCF is working to lessen the risk to children, the most innocent victims of the HIV/AIDS pandemic.

For years, CCF has been monitoring the prenatal care, nutrition and health of mothers-to-be around the world. AIDS, however, now greatly impacts safe motherhood. In a pilot program in Kenya, CCF is educating women about this very important safe motherhood issue. CCF's program in Kenya aims to prevent the spread of HIV from mother to infant by reaching women before and during pregnancy.

**Identification of Women:** As a result of CCF's focus on children, project workers come into contact with thousands of Kenyan mothers through their work with the children, such as early childhood development, immunizations and weigh-ins, as well as various health, nutrition and outreach programs. These programs provide opportunities to inform women about the need to learn their HIV status, and to refer them for counseling and testing.

**HIV Counseling and Testing:** CCF facilitates testing and counseling in communities throughout Kenya for women, before and during pregnancy, through partnerships with local health posts and voluntary counseling and testing centers.

**Antiretroviral Therapy:** Research shows that providing one tablet of nevirapine to a mother at the time of labor and one oral dose of liquid suspension to the newborn within 72 hours of birth reduces the risk of HIV transmission by almost half. For the first stage of the program, CCF has initiated nevirapine intervention in several projects in western Kenya that have nearby health centers. The second stage will involve familiarizing traditional birth attendants with the program.

**Malaria Control:** If an HIV-positive mother contracts malaria during her pregnancy, she stands an even greater

## Challenges and Solutions

**Challenge:** Men are often overlooked in education sessions about Mother-to-Child transmission because it is seen as a woman's issue. This is an oversight that adds to the stigma experienced by pregnant women who are also HIV-positive.

**Solution:** CCF Kenya's peer education program trains both men and women about HIV/AIDS and encourages the educators to share information with their peer groups. With the introduction of a special program in Kenya, male peer educators will also be trained about mother to child transmission in an effort to raise awareness among men and thereby decrease the stigmatization toward women so that women are more willing to access program services.

chance of passing on the HIV virus to her infant. Malaria makes the woman more vulnerable to maternal anemia, which can lead to low infant birth weight and related complications. Following the success of CCF's child survival program in Angola, the Kenya program uses chloroquine to provide antimalaria treatment for pregnant women whenever possible. In areas prone to malaria, like Kenya and Uganda, CCF has programs in place to provide mosquito nets and reduce the mosquito population through removal of brush and other tactics.

**Safe Motherhood:** CCF encourages its HIV-positive mothers to remain as healthy as possible through participation in its existing programs offering prenatal care, regular checkups, immunizations, and nutritional supplementation.

**Health Professional Training:** In its pilot program, CCF is working closely with community-level clinics as well as traditional birth attendants, who are the only available health workers in some remote areas. Birth attendants oversee the majority of child births in the developing world and can be instrumental in mobilizing women to take preventative action to protect their infants through the safe motherhood, HIV counseling and testing, nevirapine and malaria programs.