

# SWAZILAND PROGRAM BRIEF

Addressing the Social and Behavioral Barriers to Prevention of Mother-to-Child Transmission of HIV Through Community Dialogue:

**AN IMPLEMENTER'S GUIDE BASED ON THE ELIZABETH GLASER PEDIATRIC AIDS FOUNDATION'S SWAZILAND EXPERIENCE**



## Authors

The Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) is grateful to the numerous partners and institutions without whose support the work featured in this implementer's guide would have been impossible.

We would like to thank the staff and leadership of the Sexual and Reproductive Health Unit of the Swaziland Ministry of Health, who provided guidance and support throughout the implementation of the community dialogues.

The Shiselweni Regional Health Management Team, particularly Matron Dlamini, Matron Maphalala, and the Health Promotion Unit, played a crucial role in endorsing the dialogues at the community-level. We are grateful for the commitment and leadership of the staff members of KaMfishane Clinic, who were willing to provide guidance in developing, field testing, and refining this model.

Without the participation and in-kind contributions of various partners in Swaziland, the success of these activities would have been limited. We would like to specifically mention Population Services International, Médecins Sans Frontières, and Simomondiya Drama Group.

We are grateful to the U.S. Agency for International Development, the U.S. President's Emergency Plan for AIDS Relief, and the Gilead Foundation, for past and continued support for numerous aspects of this work.

## Authors

This issue brief was written by Maphangisa Dlamini, program officer (Swaziland), Zandile Nhleko (Swaziland), Damilola Walker (Washington, D.C.) and Caspian Chouraya (Swaziland).

The authors would also like to acknowledge the following individuals for their contributions:

Christian Pitter, Director, global technical policy, Washington, D.C.

Rufaro Guzha, Program Officer (Swaziland)

Penny Smith, Senior Technical Officer, Washington, D.C.

## Summary

EGPAF is a leading global organization that supports the provision of prevention, care, and treatment services for HIV and AIDS. EGPAF currently supports research, implementation, and advocacy activities in the United States, India, and 13 countries in Africa, through which over 5,400 sites are enabled to provide lifesaving antiretroviral therapy and services to prevent the transmission of HIV to infants.

In *Countdown to Zero, Global Plan towards the Elimination of New HIV Infections among Children by 2015 and Keeping Their Mothers Alive*, the global normative bodies set a goal of reducing the number of new infections among children by 90% and reducing the number of AIDS-related maternal deaths by more than 50%<sup>1</sup>. To achieve this goal, health systems limitations must be addressed to ensure early uptake of services, retention of mothers and their infants during pregnancy and throughout the postnatal period, and adherence to recommended regimens. However, strategies are also needed to galvanize and empower communities to confront and address the myriad social barriers that inhibit optimal health outcomes for mothers, infants, and families living with and affected by HIV and AIDS.

Since 2008, EGPAF has implemented a strategy aimed at increasing ownership and participation in PMTCT efforts, through dialogue. The community dialogue methodology utilizes facilitated dialogues to generate locally appropriate solutions. This document describes EGPAF's experience implementing this strategy in conjunction with a range of donors, local and national stakeholders.



Photo: James Pursey

# ABBREVIATIONS AND KEY DEFINITIONS

---

AIDS	acquired immunodeficiency syndrome
ANC	antenatal care
ART	antiretroviral therapy
ARV	antiretroviral
DBS	dried blood spot
EGPAF	Elizabeth Glaser Pediatric AIDS Foundation
EIMC	early infant male circumcision
FBO	faith-based organization
HIV	human immunodeficiency virus
HTC	HIV testing and counseling
liguma labomake	a traditional gathering in which women share experiences
MOH	Ministry of Health
MTCT	mother-to-child transmission (of HIV)
NGO	nongovernmental organization
PMTCT	prevention of mother-to-child transmission (of HIV)
RHMT	regional health management team
sidla inhloko	a traditional gathering of men to eat a cow's head
STI	sexually transmitted infection

# TABLE OF CONTENTS

---

Background .....	4
What Is a Community Dialogue? .....	6
How Do Community Dialogues Contribute to Achieving PMTCT Goals? .....	7
The Community PMTCT Dialogue Model.....	7
Conducting the Community Dialogue .....	10
Concluding the Community Dialogue .....	17
After the Dialogue.....	18
Insights from the Community PMTCT Dialogue Approach.....	18
References .....	20

## BACKGROUND

---

Globally, there are an estimated 34 million people living with HIV and AIDS, the majority of whom are unaware of their status<sup>2</sup>. More than 6.65 million people living with HIV and AIDS have access to lifesaving antiretroviral (ARV) medications, and the numbers of individuals newly infected with HIV and of those dying from HIV-related causes are in decline.

In low and middle income countries, between 2002 and 2010, the percentage of women tested for HIV during pregnancy has increased from less than 8% to 35%, and the coverage of ARV medications for preventing pediatric HIV infections has increased from less than 9% to 48% in the same period. The countries of Eastern and Southern Africa, which are disproportionately affected by the HIV epidemic, have made particular progress in scaling up coverage of prevention services among pregnant women. In 2010, 64% of pregnant women in this region received the recommended regimens for preventing pediatric HIV infections (in sub-Saharan Africa, coverage stood at 49%). In spite of this progress, there is much left to be done—according to the most recent reliable estimates, approximately 390,000 children become infected with HIV in 2010<sup>3</sup>.

In Swaziland, EGPAF employs a community dialogue approach to tackle the root social and behavioral barriers to enhanced uptake of critical prevention and care services. Mounting evidence from reproductive health and maternal and child health applications of the dialogue approach indicates that the approach bears promise for helping HIV-affected communities confront and address the myriad social issues that inhibit optimal care-seeking behaviors as they pursue the elimination of new pediatric HIV infections.

This brief will cover:

- An overview of the community dialogue approach, including its theoretical underpinnings;
- A detailed description of the EGPAF community dialogue methodology and its implementation in Swaziland;
- Some insights from implementing this methodology in Swaziland;
- Audience-specific tools that have been developed to guide the dialogue process

### EGPAF's Global Programs

The Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) is a leading global organization that supports the provision of prevention, care, and treatment services for HIV/AIDS. EGPAF currently supports research, implementation, and advocacy activities across 13 countries in Africa, as well as India and the United States, through which more than 5,400 sites are enabled to provide lifesaving antiretroviral therapy (ART) and services to prevent the transmission of HIV to infants.

In 2009, more than one in five pregnant women who received medicines that could prevent transmission of HIV to their infants did so through EGPAF-supported programs. By December 31, 2011, EGPAF had provided more than 14.2 million women with services to prevent transmission of HIV to their infants, and more than 12.4 million women had been tested for HIV through Foundation-supported programs<sup>4</sup>.

EGPAF-supported has also led the way in providing care and treatment services, placing a particular emphasis on the inclusion of children. As of December 2011, more than 1.6 million individuals, including more than 125,000 children, had been enrolled in EGPAF HIV care and support programs. Since enrollment began, more than 850,000 individuals have begun ARV treatment. Nearly 70,000 of those are children under the age of 15.

## **The EGPAF/Swaziland Country Program**

EGPAF has supported the government of the Swaziland since 2004, with the goal of preventing pediatric HIV infection and reducing HIV-related morbidity and mortality among women, children, and families. EGPAF works with the Ministry of Health (MOH) and health facilities to strengthen the health-care system through technical assistance and capacity development.

In 2011, the government of Swaziland expressed a commitment to work towards attaining the virtual elimination of mother-to-child transmission (MTCT) of HIV by the year 2015. HIV prevalence among pregnant women in the country is 41.1%<sup>5</sup>. With approximately 33,000 deliveries registered every year, therefore, about 13,563 infants are HIV-exposed during delivery. In 2009, an estimated 2,300 infants became infected during pregnancy, delivery, and breastfeeding. With the introduction of the 2010 WHO guidelines for prevention of mother-to-child transmission (PMTCT), more-efficacious treatment regimens are being made available for HIV-infected women and their infants, making elimination of pediatric HIV a possibility in Swaziland.

EGPAF's approach is family-centered, supporting the MOH strategy to implement the four prongs of PMTCT<sup>i</sup>. The key strategies focus on increasing access to PMTCT, including (a) scaling up comprehensive PMTCT services, (b) strengthening the maternal and child health platform, (c) reducing missed opportunities for service delivery, and (d) working with communities to address cultural norms that limit service uptake<sup>6</sup>.

## **Social Barriers to Uptake, Retention, and Adherence in PMTCT services**

In Swaziland, where patriarchy is the dominant form of social organization, deeply entrenched and gender-inequitable attitudes pose a strong challenge to attaining the government's target of eliminating pediatric HIV<sup>7</sup>. For instance, Swazi definitions of masculinity encourage high levels of sexual risk-taking by men, and inhibit care-seeking behaviors (Swazi men are expected to be 'strong' and sexually virile). Though men are traditionally described as the sole decision-makers on sexual and reproductive health issues, the burden of care-seeking and care-giving is often placed upon women - reproductive health is perceived as "women's responsibility" and clinics are largely regarded as "women's spaces."

Health belief dualism (combined use of traditional and biomedical health methods) is commonplace, and child birth is viewed as a 'natural process' which should ordinarily require little intervention. As a result, mothers often present late in pregnancy for antenatal care, and home births are common place<sup>8</sup>. These health-limiting social and cultural beliefs, compounded by high levels of HIV and AIDS stigma and denial, are associated with delayed uptake of maternal health services, poor adherence to prevention regimens, institutional births, and uptake of postnatal care, all of which must be addressed to achieve sustainable PMTCT outcomes.

EGPAF recognizes that to achieve elimination of new pediatric HIV infections, communities cannot be passive recipients of information and services, but must be instrumental in developing solutions to their health problems. As such, EGPAF-Swaziland utilizes a community dialogue methodology to build platforms for communities to discuss issues that are often left un-confronted because of taboo, stigma and shame. This engagement process builds community agency to become catalysts in transforming community beliefs and attitudes towards the issue of pediatric HIV.

## **The EGPAF/Swaziland Community PMTCT Dialogue Approach**

EGPAF started implementing its community dialogue approach in 2008, in response to the numerous sociocultural barriers that affect maternal, newborn, and child health. The community dialogues utilize guided discussions to explore the root causes of delayed care-seeking, sexual risk-taking, gender inequities, stigma, and poor communication about general and reproductive health issues among couples. Community dialogues seek to reverse limiting traditional beliefs and cultural perceptions through

<sup>i</sup> The four prongs of programs to prevent the transmission of HIV among infants includes primary prevention of HIV among girls and women of reproductive age; prevention of unwanted pregnancies among women living with HIV; ensuring women living with HIV have access to antiretrovirals to prevent HIV being passed to babies during pregnancy, delivery and breastfeeding; and HIV treatment, care, and support for women living with HIV and AIDS and their children and families

the strong involvement of men, providing a forum that draws participants from as many parts of the community as possible to exchange PMTCT information face-to-face, share personal stories and experiences, honestly express perspectives, clarify myths about health issues, and develop responses to community concerns as well as opportunities to promote health-seeking behavior.

The community dialogue approach seeks to do the following:

- Foster a family-centered approach to PMTCT by increasing men's health-seeking behavior and involvement in PMTCT
- Correct myths and misconceptions about sexual and reproductive health issues through the provision of health information
- Engage communities in identifying their own health needs and in prioritizing interventions
- Bring the voices of people into policy development, and integrate community concerns and decisions into national and decentralized plans

## WHAT IS A COMMUNITY DIALOGUE?

---

Bingham et al. define the dialogue-based community-engagement process as “an iterative turn-taking process in which each participant seeks to clarify what others believe and understand, as well as one's own beliefs and understanding (that) focuses on interpersonal context, including family relationships and social support networks as entry points for social change”<sup>9</sup>. Interpersonal communication approaches that recognize health decision-making as dynamic, iterative, and continuously subject to peer and social influences have long been utilized in public health<sup>10</sup>. A growing body of literature describes the effectiveness of the community dialogue approach in reproductive health<sup>11</sup>, maternal and child health efforts<sup>12</sup>. More recently, the approach is being applied at scale to HIV prevention efforts<sup>13</sup>.

Community dialogue draws upon a theoretical framework that recognizes individuals as agents capable of contributing to the interpretation and creation of new knowledge for local use through their participation in peer networks<sup>14</sup>. Unlike traditional information, education, and communication activities, the dialogue recognizes and builds upon community agency, capacity for reflective discourse, and collective action through two-way communication. Unlike a debate, a dialogue emphasizes listening to deepen understanding. It develops common perspectives and goals, and allows participants to express their own interests.

A community dialogue enables communities to be aware of the practices that are adverse to their members' health and provides a forum to plan interventions. Community dialogues foster a spirit of unity within the community as they work together to seek and bring to fruition, solutions to their health issues. Community leaders are given an opportunity to exert a positive influence on the community by encouraging health-seeking behavior and discouraging risky health behavior.

# HOW DO COMMUNITY DIALOGUES CONTRIBUTE TO ACHIEVING PMTCT GOALS?

---

Dialogues help achieve goals for the prevention of mother-to-child transmission (PMTCT) in the following ways:

- Enable the entire community to be involved in preventing mother-to-child transmission of HIV; all attendees (men, women, youth, community leaders, etc.) can participate in discussions
- Raising critical consciousness about the relationship between stigma and health outcomes
- Facilitating the discussion of topics that would not normally be talked about in other forums and providing opportunities for reflective discussion
- Providing an avenue for men to receive information on health issues
- Helping identify barriers to positive change and uncovering innovative ideas
- Launching new initiatives and strengthening the impact of existing community improvement partnerships
- Focusing corporate and organizational investment toward greater community benefit
- Generating local media attention to male involvement issues and PMTCT
- Giving voice to marginalized and underserved segments within the communities
- Enabling leaders of all sectors see their role in building healthy, sustainable communities

## THE COMMUNITY PMTCT DIALOGUE MODEL

---

### The Community Entry Process

The community dialogue can be organized to respond to various social issues. In some cases, a specific event or series of events may present the perfect opportunity to introduce the dialogue. Whatever the objectives of the dialogue, it is critical to gain the support and buy-in of key institutions and gatekeepers at the inception. If executed with care, the community entry process should secure leadership buy-in and consensus around the priority groups and the roll-out process.

Successful community entry is contingent upon identifying all relevant structures and authorities whose formal and informal approval is necessary for successful implementation at all levels, including community leaders and community health-care workers, regional health management teams, and facility staff. In EGPAF-Swaziland's model, the community entry process started with discussions with the Sexual and Reproductive Health Unit (SRHU) of the Ministry of Health, under which PMTCT activities are coordinated nationally in Swaziland. These initial discussions were intended to ensure alignment with the national work plan and priorities. Planning meetings were held with regional health management teams (RHMTs) to select the priority communities. Management personnel from health facilities in these communities were instrumental in constituting a planning committee including staff members from the health facility, community development workers, and one or two members of the chief's inner circle.

### Planning a PMTCT Community Dialogue

In Swaziland, planning teams hold a minimum of three (3) meetings prior to a dialogue. The purpose of the pre-dialogue meetings is to bring the planning team together and develop a shared vision, discuss the issues that need to be addressed at the community dialogue, identify the target population, and work on logistics for the community dialogue.

### Selecting the planning team

While the local clinic or health facility provides a convenient coordination point, other organizations working with the local clinic and the local community should be part of the planning and implementation process in order to foster shared ownership of the activity. A team approach to convene a dialogue will help to build ownership and equitably distribute the tasks involved.

In Swaziland, the planning team has included representatives from EGPAF and the National Health Education Unit; RHMTs; Regional Health Promotions Officers; health facility staff members; and community members, including rural health motivators and those working in youth structures.

### Conducting a rapid situation analysis with the members of the planning team

It is important for all members of the planning team to understand the unique communication needs of the community in order to ensure that the community dialogue addresses these needs effectively. Before detailed planning for the dialogue commences, the members of the planning committee should explore the major health issues, myths, misconceptions, threats, power structures, communication channels, resources, and assets of their community. The general steps outlined below may be helpful in guiding the situation analysis:

- Examine the general trends and patterns for the major PMTCT outcomes (*e.g. What proportion of women took the maternal ARVs? What proportion of infants took the infant ARVs? What proportion of infants returned for testing at 6 – 8 weeks? What were the general results for infants tested at 6 – 8 weeks? etc.*)
- Explore the main gaps contributing to these trends and identify the desired changes (*e.g. Do women present for ANC early enough? What are the rates of institutional deliveries? etc.*)
- Discuss and examine the social and behavioral obstacles to change (*e.g. What are the specific health beliefs and health-seeking behaviors in this community? What are the prevalent myths and misconceptions – if any? Do specific gender and power structures limit access and utilization of health services for certain populations? etc.*)
- Describe current community context (*e.g. Are most people unaware of the health status of their communities? Are communities in denial? Are community leaders and major institutions willing and ready to consider the need for change and find solutions to the major challenges? Are people resistant to change and unwilling to work together? etc.*)
- Examine potential resources (*e.g. What are the major communication channels? What kinds of community structures could be mobilized? What are the media outlets? etc.*)

### Defining the broad aims and target population

After completing the situation analysis, the planning committee should come to some consensus on the broad issues to be highlighted and discussed during the dialogue, and identify the key groups that should be targeted. The following questions may

---

During the initial community dialogues in KaMfishane, the clinic staff and the Shiselweni regional health team as well as EGPAF staff held sole responsibility for planning, and other partners were informed about the date, the venue, and what they were required to do.

Without being briefed on the goals and aims of the community dialogue process, officers from participating partner non-governmental organizations (NGOs) tended to dominate the conversation, stifling the opinions of male community members—the community members expected the NGO officers to lead the discussions as they had from the beginning of the planning.

For subsequent dialogues, local partners who intend to participate in the dialogues have been involved in the planning meetings, where the importance of getting the community's opinions is stressed and roles are clarified (NGO staff are expected to answer only health-related questions or ask a follow-up question on a submission).

---

guide the selection of the aims and target population:

- What are the largest health gaps and challenges in this community?
- Are there a few root causes (myths, misconceptions, practices, beliefs) driving these health issues?
- Which age, social, or gender groups appear to be more affected by the key health issues?
- Why are specific groups more affected than others by the key health issues?
- Which age, social, or gender groups have an influence on the health outcomes of the most affected groups?

### **Developing a mobilization plan**

Prior knowledge of the community is important for identifying the mechanisms that will work best to gather a broad cross-section of the community for the dialogue. For this reason, it is important to have a community member as part of the planning and coordinating team. A combination of the following mechanisms can be used to invite people for the community dialogue:

- Seek audience with community leaders
- Ask community leaders and other influential members of the community to help rally the public
- Identify appropriate media for the audience to be reached—for example, a radio announcement
- Post announcements in grocery stores, pharmacies, or schools in the community
- Invite yourself to various group meetings in the community to get the word out

### **Developing an implementation plan**

The planning committee develops a plan of action for the community dialogue and ensures that commitments are secured from health facility staff, local NGOs, and community institutions to realize this plan. Clear roles and responsibilities should be assigned, covering the planning and implementation of the dialogue.

1. Logistics
  - a. Secure the date, venue, shelter, furniture, and refreshments
  - b. Set an agenda or program for the day's activities
  - c. Plan other activities for the day (e.g. HIV testing and counseling - HTC, blood pressure checks, blood glucose checks)
  - d. Invite guests or other people of influence in the community
2. Implementation planning
  - a. Assign roles and responsibilities for the crucial dialogue activities (e.g., key speeches; edutainment opportunities such as music, dance, or drama; mobile services)
  - b. Assign roles and responsibilities for post-dialogue activities (e.g., writing and disseminating a report, providing feedback to the community, conducting follow-up activities)
  - c. Develop a budget (if needed)
3. Identification of facilitators who should be part of the pre-dialogue meetings
  - a. Ensure there is one same-gender facilitator for each of the major target groups that will participate in the dialogue
  - b. Ensure there is at least one health facility staff member or technical resource person on site to answer questions that arise during the dialogue

# CONDUCTING THE COMMUNITY DIALOGUE

It is best to start the day's activities moderately early, with a pre-dialogue meeting to ensure coordination across partners and to reassign roles and responsibilities if necessary. While health services should be prepared early in the day, it is advisable that they be made available later in the day, after the day's activities have commenced. This will safeguard against the temptation to utilize services without participating in the community dialogue activities.

In general, the community dialogues start with a feature presentation, which will serve as a conversation trigger (as depicted in figure 1 to the right). This could be a short drama presentation, movie clip, or audio piece. The feature presentation is intended to be an entertaining way to start discussion and thinking on the day's issue.

Breakout sessions are ideal and, if well facilitated, will allow members from homogenous groups to discuss their perspectives on an issue of importance to the theme or health concerns of the dialogue. Table 1 presents a sample agenda from the Swaziland community dialogues.

## The Conversation Trigger

In Swaziland, the oral tradition is a cornerstone of community life. History and tradition are handed down across generations by spoken word. However, community members may not be comfortable dealing

with the health system and health issues through dialogue, and may be hesitant to initiate honest and open conversation. A feature presentation such as a skit, drama performance, forum theater, audio narration, or movie clip is a useful device for presenting health issues in a format that is accessible and familiar to people, and reflects their daily realities.

The ideal conversation trigger should be short, impactful, and creative. To avoid conflict and controversy, it should not be politicized or sensationalized.

## The Starter Conversation

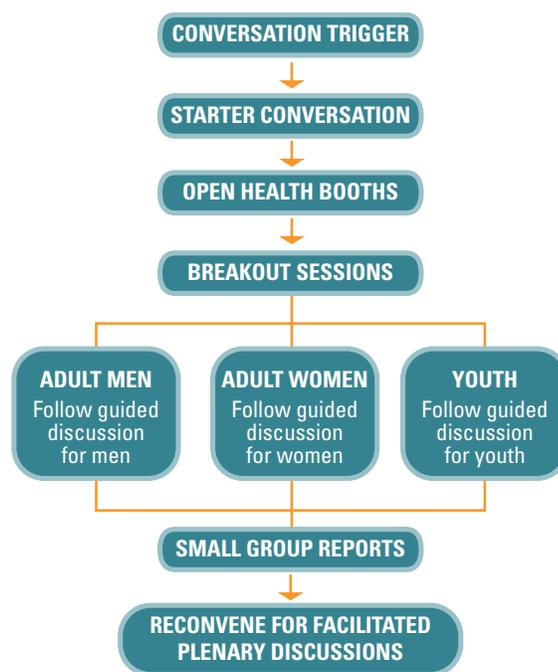
Following the conversation trigger (the feature presentation), a brief facilitated conversation on the audience's reactions can help to open the space for reflective dialogue, particularly if the conversation focuses on the links between the conversation trigger and what participants observe in their communities, peer groups, social circles, and personal lives.

## Service Provision at the Community Dialogue

The communities with the largest health service uptake challenges are also likely to be underserved with critical health services. Providing on-site services is an opportunity to address any challenges with health service access that the community—or segments of the community—might be facing. The convenience of services provided at community-level might also be a powerful incentive for community members to participate in a dialogue. Where possible, integrated services that meet the needs of a broad cross-section of the population (or a few key segments) should be provided.

Because services are often provided in makeshift structures, managing the confidentiality and privacy of interactions between

Figure 1



**Table 1. Sample Agenda**

TIME FRAME	ITEM	RESPONSIBLE PARTY	NOTES
9:00 a.m.	Pre-dialogue meeting	EGPAF community linkages team	All partners, NGOs, facilitators, scribes, and resource persons meet to allocate tasks in facilitation, share discussion tools, etc.
10:00–10:05 a.m.	Opening prayer (optional)	Local clergy selected by area chief	
10:05–10:15 a.m.	Welcome remarks by community representative	Chief's representative	
10:15–10:25 a.m.	Why we are here (PMTCT overview)	EGPAF representative	
10:25–10:30 a.m.	Introduction of guests, organizations, services	Master of ceremonies	All guests from partner NGOs, services, and information desks are introduced to audience.
10:30–11:15 a.m.	Presentation of the theme	Simomondiya Drama Group	A drama by a group of soldiers from the Swaziland army, addressing PMTCT issues: HIV testing and counseling HIV stigma Discordant couples Lack of disclosure ART adherence Breastfeeding Partner support in antenatal care
11:15 a.m.–12:45 p.m.	Breakout sessions (sidla inhloko and liguma labomake)	Four facilitators: Boys' group Girls' group Mothers' group Elderly men's group	Discussions are guided by the dialogue checklist. Scribes capture attendance and discussions. Resource persons address concerns, questions, and myths.
12:45–12:50 p.m.	Small group reports	Group facilitators	Each small group elects one person to report its summary back to the larger group
12:45–12:50 p.m.	Closing remarks	Chief, member of parliament, or mayor	

clinicians and community members is often a concern. To maintain auditory and visual privacy, the service booths are usually set up at a little distance from the main activities of the dialogue.

There is a risk that community members will attend the community dialogue to receive services and forgo participating in the discussion sessions. To manage this tendency, community members are specifically instructed to avoid lining up for services all at the same time.

### Handling the Breakout Sessions

The breakout sessions are the heart of the day's activities for the community dialogue and need to be handled by skilled facilitators who can put the group at ease, move conversations forward purposefully, and manage conflict if it arises. These sessions are best facilitated by someone who is familiar with the community and its challenges, and is of the same gender as the group members.

Where resources allow, the facilitator should be assisted by a note-taker, who records the highlights of the breakout conversation and ensures that the points to be reported at the plenary session are accurately reflected in the minutes.

In line with Swazi cultural and traditional norms, breakout sessions are segregated by gender and by age, with specific guided questions for the health and social issues that each target population is likely to perceive as important. The discussion guides are intended not to be prescriptive but to provide entry points for deeper dialogue on issues of critical importance for health and PMTCT outcomes (sample discussion guides for youth and women are featured as Tables 2 and 3).

Having a separate youth breakout session presents an important opportunity to help youth explore and reflect upon the practices that drive HIV risk. Between the ages of 15 and 24, youth are beginning to act according to perceived gender scripts and social norms, but they are less set in their perspectives than older people. Youth are more likely to openly question tradition, customs, and social expectations. Generally, youth in this age group may be more willing than their older counterparts to openly express

---

The initial Swaziland community dialogues provided HIV counseling and testing services only. At these initial dialogues, men voiced concerns about the exclusive HIV focus and expressed dissatisfaction that services did not address health issues comprehensively. To remedy this omission, subsequent community dialogues have offered different services (blood pressure and blood glucose checks as well as HIV services). The blood glucose checks are popular with the older generation of men (40+), who fear impotence due to diabetes. In the future, TB services provided by the MOH TB Unit will be integrated into the community days.

---

their observations, experiences, and thoughts in a mixed-gender setting.

---

In early dialogues, mothers-in-law and daughters-in-law were grouped together. This arrangement did not work well because the younger women, understandably, were hesitant to talk about their sexual practices and issues in the presence of their mothers-in-law. Holding separate breakout discussions for older and younger women helped overcome this barrier. Each group hears a summary of what was discussed in the other group during the report-back session.

---

Facilitators should be on the lookout for youth who appear to be under duress and may need counseling and support. Some youth may seek out the facilitator after the dialogue to ask for advice. The facilitator should be prepared to provide a referral for health and social services. Some youth may fit several demographic categories (a female youth, for example, may also be a wife and mother). The decision on which breakout discussion to attend should be left to the youth.

In Swaziland, stereotypes about what it means to “be a man” limit men’s care-seeking, whether curative or

**Table 2. Discussion Guide for Male and Female Youth Under the Age of 24**

<b>PRONG 1: TARGETED PRIMARY PREVENTION AMONG GIRLS AND YOUNG WOMEN OF CHILDBEARING AGE</b>	
Key discussion points	<p>Young people’s views on abstinence, sex, condoms, and HIV counseling and testing</p> <ul style="list-style-type: none"> <li>• What can young people do to prevent sexually transmitted infections (STIs), including HIV?</li> <li>• What do they do when they discover they have an STI? Do they go to the clinic or get their own remedies?</li> <li>• Do young people undergo HIV counseling and testing before engaging in a sexual relationship?</li> <li>• What are the barriers to abstinence among youth?</li> <li>• Is secondary abstinence possible?</li> <li>• What can be done to delay sex debut among youth?</li> <li>• Do boyfriends have the right to have sex with their girlfriends?</li> <li>• What are the challenges that young people generally have using condoms correctly and consistently?</li> <li>• Are girls able to negotiate for condom use with their boyfriends?</li> <li>• What are the views of young men on voluntary medical male circumcision?</li> <li>• Where do young people get information on sexual and reproductive health issues (e.g. parents, friends, media, clinic, etc.)?</li> <li>• What are the barriers to HIV testing for young people?</li> </ul>
<b>PRONG 2: PREVENTION OF UNINTENDED PREGNANCIES IN HIV-POSITIVE GIRLS AND YOUNG WOMEN</b>	
	<p>Pre-conceptual care, readiness for couple to conceive in a healthy state</p> <ul style="list-style-type: none"> <li>• Are pregnancies among the youth ever planned?</li> <li>• If a young girl has HIV, is it okay for her to get pregnant? What does she need to do to ensure an HIV-negative baby?</li> <li>• If a young man knows that his girlfriend is HIV-positive, how does he support her in avoiding an unwanted pregnancy?</li> <li>• What role do young men play in supporting their girlfriends to prevent unwanted pregnancies?</li> </ul>
<b>PRONG 3: PREVENTION OF TRANSMISSION FROM HIV-POSITIVE YOUNG MOTHERS TO INFANTS</b>	
	<p>ART, disclosure, infant and young child feeding</p> <ul style="list-style-type: none"> <li>• What stops young women from going to the clinic early when they are pregnant?</li> <li>• What are the barriers to accessing ART for young people?</li> <li>• What support should young men give when their partners are pregnant?</li> <li>• Do young men want to know if their pregnant girlfriends test positive for HIV at the clinic?</li> <li>• Do young men go to the clinic when their girlfriends inform them that their presence is required?</li> </ul>
<b>PRONG 4: CARE AND SUPPORT FOR WOMEN, THEIR CHILDREN, AND THEIR FAMILIES</b>	
	<p>Ongoing care and support for women and children</p> <ul style="list-style-type: none"> <li>• Where can young people get support if they are diagnosed with HIV?</li> <li>• How can young people support peers who disclose their HIV-positive status?</li> <li>• How can young people support their partners and children who have HIV?</li> <li>• If diagnosed as HIV-positive, would the breakout participants join a support group that has other young people living with HIV?</li> </ul>

preventive. Swazi traditional culture also ascribes high value to fertility and childbearing, with often adverse outcomes related to optimal and healthy child spacing, parity, and institutional deliveries. A well-facilitated breakout session should help participants examine and explore how traditions, customs, rites, and beliefs result in different health-seeking behaviors for men and women. The content of breakout sessions may help to identify opportunities for strengthening the demand for services and help to gauge the community's perspective on how to improve services.

**Table 3. Discussion Guide for Adult Women**

<b>PRONG 1: TARGETED PRIMARY PREVENTION AMONG WOMEN OF CHILDBEARING AGE</b>	
Key discussion points	<p>Women's views on condom use</p> <ul style="list-style-type: none"> <li>• What can women do to prevent the spread of HIV in their communities?</li> <li>• Do women use condoms? If not, what are the hindrances to condom use?</li> <li>• How do male partners feel about condom use? Are women able to negotiate for condom use?</li> <li>• Is the facility giving women enough health education on prevention?</li> <li>• What can the facility do to assist women in preventing HIV?</li> </ul>
<b>PRONG 2: PREVENTION OF UNINTENDED PREGNANCIES IN HIV-POSITIVE GIRLS AND YOUNG WOMEN</b>	
	<p>Pre-conceptual care, readiness for couple to conceive in a healthy state, low viral load</p> <ul style="list-style-type: none"> <li>• Are pregnancies ever planned? Why or why not?</li> <li>• How do male partners react to family planning? What role do they play in supporting their wives/girlfriends in preventing pregnancy?</li> <li>• Do women see the need to visit the facility for monitoring and care before deciding to become pregnant?</li> <li>• Do women in the community ever consider tubal ligation as a means of family planning?</li> </ul>
<b>Prong 3: Prevention of transmission from HIV-positive young mothers to infants</b>	
	<p>Home delivery versus facility delivery, ART, disclosure, and breastfeeding</p> <ul style="list-style-type: none"> <li>• Why do women book late for antenatal care (ANC)?</li> <li>• What are the feelings regarding HIV counseling and testing during pregnancy?</li> <li>• For women who opted to test for HIV during pregnancy, what was the motivation?</li> <li>• For women who opted out of testing, what were the reasons?</li> <li>• What are the barriers to accessing ART for women?</li> <li>• What makes women opt to deliver at home? What are the advantages of home delivery? What are the dangers of home delivery?</li> <li>• What are the hindrances to facility delivery? What are the benefits of facility delivery?</li> <li>• What prevents women from breastfeeding exclusively?</li> <li>• Who exerts the most influence at home in terms of infant feeding?</li> <li>• What support would women like to receive from their partners during pregnancy?</li> <li>• What are the feelings about care of HIV-exposed infants in terms of the medications cotrimoxazole and nevirapine?</li> </ul>
<b>Prong 4: Care and support for women, their children, and their families</b>	
	<p>Ongoing care and support for women and children</p> <ul style="list-style-type: none"> <li>• Where can women get support if they are diagnosed with HIV?</li> <li>• What support do women living with HIV receive from their families? What support would they want to receive from their families/spouses?</li> <li>• If diagnosed as HIV-positive, would breakout participants join a support group that has women living with HIV?</li> <li>• Do participants know or have they heard about any support groups in the community?</li> <li>• Do they understand the role of support groups?</li> </ul>

## Facilitating the Plenary Dialogue

Upon completion of the short breakout sessions, the highlights of the breakout groups are shared, and opportunities are provided for community members to respond to issues of interest to them.

### DIALOGUE FACILITATION

The facilitator's role requires good listening skills. The facilitator must also help set and follow ground rules for participation in the dialogue. Establishing rules helps to create a safe environment for openness and sharing. The facilitator's basic responsibility is to the group as a whole, while also considering each person's individuality and level of comfort.

A good facilitator should strive to do the following:

- Establish ground rules for the group. Set a relaxed and open tone.
- Stay neutral. The facilitator should not share personal views or try to advance an agenda on the issue. The facilitator is there to serve the discussion, not to join it.
- Keep track of who is contributing and who is not. The facilitator should help to keep the group focused on the content of the discussion and monitor how well the participants are communicating with each other—who has spoken, who has not, and whose points have not yet received a fair hearing.
- Follow and focus the conversation flow. To help keep the group on topic, it is helpful to occasionally restate the key question or insight under discussion. It is important to guide gently yet persistently. The facilitator might ask, "How does your point relate to the topic?" or state, "That's an interesting point, but let's return to the central issue." It is critical to keep careful track of time.
- Do not fear silence. It is alright if people are quiet for a while. When deciding when to intervene, err on the side of nonintervention. Sometimes group members only need more time to think through alternatives or to consider what has just been said.
- Accept and summarize expressed opinions. Acknowledging contributions shows respect for each participant in the group. It is important for the facilitator to make it clear that dialogue discussions involve no right or wrong responses.
- Anticipate conflict and attend to the ground rules. When conflict arises, it is important to explain that disagreement is to be expected. It is useful to remind participants that conflict must stay on the issue and must not become personal. It might be necessary to appeal to the group to help resolve the conflict. Stop and refer to the ground rules several times throughout the discussion.
- Close the dialogue. Participants should be given a chance to talk about the most important thing they gained from the discussion. They should be asked to share any new ideas or thoughts they have had as a result of the discussion and to think about what worked and what didn't. It is important to close the dialogue by thanking everyone for participating.

## DEALING WITH CHALLENGES DURING A DIALOGUE

In order to effectively handle challenging situations, the dialogue facilitator must anticipate them and be prepared. Each dialogue is a unique experience, providing new opportunities for the discussion leader. The following scenarios present some possible challenges and offer some guidelines for handling them:

The group is slow to respond to the process

- Check to determine whether the instructions have been understood.
- Restate the purpose of the process and how it should be carried out.
- Assure the community that the purpose of the process is to share different insights, experiences, and personal reflections on the topic. However the members choose to participate is valuable.

One or a few members dominate the dialogue

- Reiterate instructions about respecting time limits.
- Invite participants to be conscious of each person's having time to share his or her reflections, ideas, and insights.
- Invoke the ground rule "It is important to share time."
- Tell the group you want to hear from those who have not said much. Participants will look to you to restrain domineering members.
- Consider whether those dominating the dialogue may be doing so because they feel they have not been heard. Restating the essence of what they have expressed can show that you have understood their point of view.

A participant walks out of a group following a heated conflict

- Remember that the best way to deal with conflict is to confront it directly.
- Remind participants that they were told initially to expect conflict but that they agreed to respond to differences respectfully.
- Intervene immediately to stop name calling, personal attacks, and threats.
- Consider whether those dominating the dialogue may be doing so because they feel they have not been heard. Restating the essence of what they have expressed can show that you have understood their point of view.

## CONCLUDING THE COMMUNITY DIALOGUE

Upon completion of the plenary dialogue, the facilitator should thank the group for taking the time to share ideas and personal values. Ideally, the participants should explore and plan some concrete, realistic possible actions, and who might be responsible for leading these, but they should not feel obliged to do something together. The note-taker may provide a summary of the lessons learned or key insights from the dialogue.

**Table 4. Fact sheet for pre-dialogue planning partners**

FACT SHEET FOR PRE-DIALOGUE PLANNING PARTNERS (DRAMA GROUPS, FACILITATORS, AND SPEAKERS)	
Early enrollment	<ul style="list-style-type: none"> <li>Prospective mothers should attend ANC clinic as soon as they miss or suspect they have missed one monthly period</li> <li>Fathers should accompany mothers, preferably on the first visit to the clinic</li> <li>Father and mother should plan for facility delivery, selecting the facility together</li> </ul>
Why fathers should attend ANC	<ul style="list-style-type: none"> <li>To show or give emotional support to the female partner</li> <li>For screening of all STIs including HIV (condom usage should be discussed)</li> <li>For discussing family planning</li> <li>To discuss early infant male circumcision and its benefits</li> </ul>
ARV prophylaxis	<ul style="list-style-type: none"> <li>HIV-positive mothers are given nevirapine to use at the beginning of labor to reduce chances of infecting the infant during birth</li> <li>All HIV-positive mothers (14 weeks and above) to adhere to zidovudine twice a day throughout pregnancy</li> <li>All pregnant mothers to take cotrimoxazole throughout pregnancy to prevent the occurrence of opportunistic infections</li> <li>During delivery, HIV-positive mothers will be provided with three different medicines (lamivudine, zidovudine, and nevirapine)</li> </ul>
Breastfeeding	<ul style="list-style-type: none"> <li>All infants should be breastfed exclusively for 6 months because breast milk carries some antibodies that could protect the child from childhood illnesses</li> <li>From 7 to 12 months the child can start complementary feeding (i.e. breastfeeding with other added foods)</li> <li>Rapid HIV test at 12 months</li> <li>If the HIV test is positive, confirm with dried blood spot test. If positive, continue breastfeeding (because the child is already positive); if the HIV test is negative, gradually wean the child</li> </ul>
Early infant male circumcision (EIMC)	<ul style="list-style-type: none"> <li>The best time to have a child circumcised is between 12 hours and 8 weeks of age</li> <li>Advantages of EIMC: fast healing, no need for sutures, few complications (pain, bleeding, and wound gaping) because penis is less developed and child has infrequent erections</li> <li>The penis is made numb by local anesthesia</li> <li>Infants eligible for EIMC are 8 weeks or less, birth weight at least 2.5 kg, not born premature, in good health, no penile abnormalities, no family history of blood disorders</li> </ul>
Adult male circumcision	<ul style="list-style-type: none"> <li>Benefits: Reduced risk of HIV (60%), improved hygiene, reduced risk of urinary tract infections, prevention or treatment of phimosis, reduced risk of some STIs, future reduced risk of penile cancer</li> </ul>
Ongoing support	<ul style="list-style-type: none"> <li>Dried blood spot test done at 6 weeks and rapid test given at 12 months to confirm HIV status</li> <li>Children found to be HIV-positive are given ARVs right away (half of children not initiated die within the first 2 years of life)</li> </ul>

## AFTER THE DIALOGUE

---

The planning/coordinating team should meet not more than a few weeks after the dialogue to review successes and challenges met during the dialogue, including the following issues:

- What worked well?
- What did not work well?
- What can be done better next time?
- Were the goals of the dialogue met?
- What follow-up actions are necessary to ensure that the dialogue achieves sustainable outcomes in this community?

A dialogue report should be prepared and distributed to key stakeholders in the community. The planning committee also needs to consider who else would benefit from receiving the results of the dialogue. People or groups that should receive a copy of the report include community leaders, facility staff members, municipal governments, rural teams, local organizations, partners, the RHMT, and local media.

## INSIGHTS FROM THE COMMUNITY PMTCT DIALOGUE APPROACH

---

### **Adapting the Contents of a Community Dialogue to Each Community's Unique Needs**

While the community PMTCT dialogue utilizes the four-pronged model as its primary technical framework, the social and cultural barriers that limit the attainment of optimal health outcomes will differ from community to community. For the community dialogue to be effective, the program team must be flexible in its implementation of the four-pronged dialogue model. For instance, in one Swazi community, a local herb known as jikisa umgcwabo (“postpone your funeral”) was known to be widely used, particularly by people living with HIV, some of whom substituted it for adherence to their ARVs. This situation was raised by the planning committee during the course of the pre-dialogue meetings. Messages on the danger of this practice were incorporated into the drama piece that served as the feature presentation of the community dialogue.

### **Ensuring Long-Term Results, Ownership, and Sustainability**

Each community will have a unique health awareness profile prior to and after each community dialogue. Communities with higher levels of social capital might be more ready to move from dialogue to concrete action in response to their health needs. Regardless of the target community's profile, it is likely that numerous dialogues and consistent postdialogue follow-up will be necessary to achieve sufficient community-level exposure or coverage and generate the desired levels of behavior change. The planning committee members and participants in early dialogues may be useful resources for determining the number and frequency of dialogues to be scheduled, and to identify recommended follow-up actions after each dialogue.

The intensity of community dialogues and follow-up activities required to achieve the desired change may demand concerted financial and human resources without the community's participation. It is important for community institutions, leaders, and members to be involved in the planning and implementation as early in the program of activities as possible.

**Table 5. Partner roles and responsibilities**

ORGANIZATION	ROLE/RESPONSIBILITY
National NGOs	Offer specialized healthcare services (such as HIV testing and counseling) Make in-kind and material donations
Health Promotion Unit (Ministry of Health)	Provide technical resource persons Assist with health messaging
Public health units	Provide primary healthcare services
TB Unit (Ministry of Health)	Provide TB screening and sputum collection
Health facility	Facilitate the dialogue and follow-up activities Provide technical resource persons Plan activities Serve as entry point Provide referral services
RHMT members	Take the lead in action plan implementation Coordinate partners, serving as regional health leadership
Health committees (revive those that have ceased operations)	Take up action plan implementation at community-level

## REFERENCES

---

- <sup>1</sup> Joint United Nations Program on HIV/AIDS (UNAIDS). *Global Plan Towards the Elimination of New HIV Infections among Children by 2015 and Keeping Their Mothers Alive: 2011–2015*. [http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/20110609\\_JC2137\\_Global-Plan-elimination-Hiv-Children\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/20110609_JC2137_Global-Plan-elimination-Hiv-Children_en.pdf). Published 2011. Accessed May 29, 2012.
- <sup>2</sup> UNAIDS. *UNAIDS Report on the Global AIDS Epidemic, 2010*. [http://www.unaids.org/globalreport/global\\_report.htm](http://www.unaids.org/globalreport/global_report.htm). Published 2010. Accessed June 26, 2012.
- <sup>3</sup> World Health Organization (WHO), United Nations Children's Fund (UNICEF) and the Joint United Nations Programme on HIV/AIDS (UNAIDS). *Global HIV/AIDS Response: Epidemic update and health sector progress towards Universal Access, Progress Report 2011*, November 2011. [http://www.who.int/hiv/pub/progress\\_report2011/en/index.html](http://www.who.int/hiv/pub/progress_report2011/en/index.html). Published 2011. Accessed July 5, 2012.
- <sup>4</sup> GLASER database. Washington, DC: Elizabeth Glaser Pediatric AIDS Foundation. Accessed May 16, 2012.
- <sup>5</sup> Swaziland Ministry of Health. *12th Round of National HIV Serosurveillance in Women Attending Antenatal Care Services at Health Facilities in Swaziland*. Mbabane, Swaziland; 2010.
- <sup>6</sup> Elizabeth Glaser Pediatric AIDS Foundation. *Swaziland Fact Sheet: Eliminating Pediatric AIDS in Swaziland*. Washington, DC; 2011.
- <sup>7</sup> Buseh AG, Glass LK, McElmurry BJ. Cultural and gender issues related to HIV/AIDS prevention in rural Swaziland: A focus group analysis. *Health Care Women Int.* 2002;23:173–184.
- <sup>8</sup> Thwala SB, Holroyd E, Jones LK. Health belief dualism in the postnatal practices of rural Swazi women: An ethnographic account. *Women and Birth.* 2011 Nov 22. [Epub ahead of print]
- <sup>9</sup> Bingham A, Drake JK, Goodyear L, Gopinath CY, Kaufman A, Bhattarai S. The role of interpersonal communication in preventing unsafe abortion in communities: the dialogues for life project in Nepal. *Journal of Health Communication.* 2011; 16 (3): 245-63. March, 2011
- <sup>10</sup> Figueroa M. E., Kincaid D. L., Manju R., Lewis G. *Communication for social change: An integrated model for measuring the process and its outcomes*. New York: The Rockefeller Foundation; 2002.
- <sup>11</sup> Daniel E. E., Masilamani R., Rahman M. The effect of community-based reproductive health communication interventions on contraceptive use among young married couples in Bihar, India. *International Family Planning Perspectives.* 2008;34:189–197
- <sup>12</sup> Manandhar D. S., Osrin D., Shrestha B. P., Mesko N., Morrison J., Tumbahangphe K. M., et al. Effect of a participatory intervention with women's groups on birth outcomes in Nepal: Cluster-randomised controlled trial. *Lancet.* 2004;364:970–979
- <sup>13</sup> FHI360/C-Change. *Community Conversation Toolkit for HIV Prevention (English)*. December 2010.
- <sup>14</sup> Valente T. W., Fosados R. Diffusion of innovations and network segmentation: The part played by people in promoting health. *Sexually Transmitted Disease.* 2006; 33:S23–31.



Photo: James Pursey



# ELIZABETH GLASER PEDIATRIC AIDS FOUNDATION

## WASHINGTON, D.C.

1140 Connecticut Avenue, N.W. (Suite 200)  
Washington, D.C. 20036  
Phone: 202-296-9165  
Fax: 202-296-9185  
info@pedaids.org

## LOS ANGELES, CA

11150 Santa Monica Boulevard (Suite 1050)  
Los Angeles, CA 90025  
Phone: 310-314-1459  
Fax: 310-314-1469  
info@pedaids.org

## GENEVA

WCC Center  
150, Route de Ferney  
1 Route des Morillons  
PO Box 2100  
Bureaux Rhône 168 et 169  
CH-1211 Geneva 2, Switzerland  
Phone: +41 22 791 6088/457

## CAMEROON

Cameroon Baptist Convention Health Board  
P.O. Box 1 Bamenda  
North West Province  
Cameroon

## CÔTE D'IVOIRE

2 Plateaux les Vallons, Rue J 50  
08 BP 2678 Abidjan 08  
Côte d'Ivoire  
Phone: 225-22-41-45-05  
Fax: 225-22-41-45-46

## DEMOCRATIC REPUBLIC OF CONGO

Avenue Colonel Mondjiba n°63  
Kinshasa Gombe  
Concession COTEX - Bâtiment n°10 B1  
République Démocratique du Congo  
Phone: +243 82 382 42 48

## INDIA

EGPAF India Consortium Office  
c/o SAATHII-Hyderabad  
H # 1-4-880/2/36/1  
New Bakaram, Gandhi Nagar  
Hyderabad-500 080  
India  
Phone: 040-27654688

## KENYA

Ariel House  
Westlands Avenue  
Off David Osieli Road  
P.O. Box 13612 – 00800  
Nairobi, Kenya  
Phone: +254 20 44.54.081/2/3  
Fax: +254 20 44.54.084

## LESOTHO

Sechaba House, 1st Floor  
4 Bowker Road  
P.O. Box 0166  
Maseru West 105  
Lesotho  
Phone: +(266) 22311662  
Fax: +(266) 22312729

## MALAWI

Green Heritage Building  
P.O. Box 2543  
Lilongwe, Malawi  
Phone: +265-1772-052  
Fax: +265-1772-050

## MOZAMBIQUE

Av. Kwame Nkrumah, n°417  
C.P.1392 (Post Office Box)  
Maputo, Mozambique  
Phone: +258-21488904  
Fax: +258-21488909

## RWANDA

Rue du lac Mpanga #10  
Avenue de Kiyovu  
B.P. 2788 Kigali, Rwanda  
Phone: +250 (0)252570583  
Fax: +250 (0)252570584

## SWAZILAND

MTN Office Park  
Karl Grant Street  
Mbabane  
Phone: +268-2404-8081  
Fax: +268-2409-0026

## TANZANIA

P.O. Box 1628  
Plot # 8 & 10, off Haile Selassie Road  
Oysterbay  
Dar es Salaam  
Tanzania  
Phone: +255-22-260-1692

## UGANDA

EGPAF/Kampala:  
Plot 18A, Kyadondo Road  
P.O. Box 21127  
Kampala, Uganda  
Phone: +256 312264380  
STAR-SW office (Mbarara):  
Plot 13, McAllister Road  
P.O. Box 881  
Mbarara, Uganda  
Phone: +256 485420160

## ZAMBIA

P.O. Box 39111  
Reliance House  
Thabo Mbeki Road  
Lusaka, Zambia  
Phone: 260 211 256 481

## ZIMBABWE

107 King George Road, Avondale  
Harare, Zimbabwe  
Phone: +263-(0)4-302144