



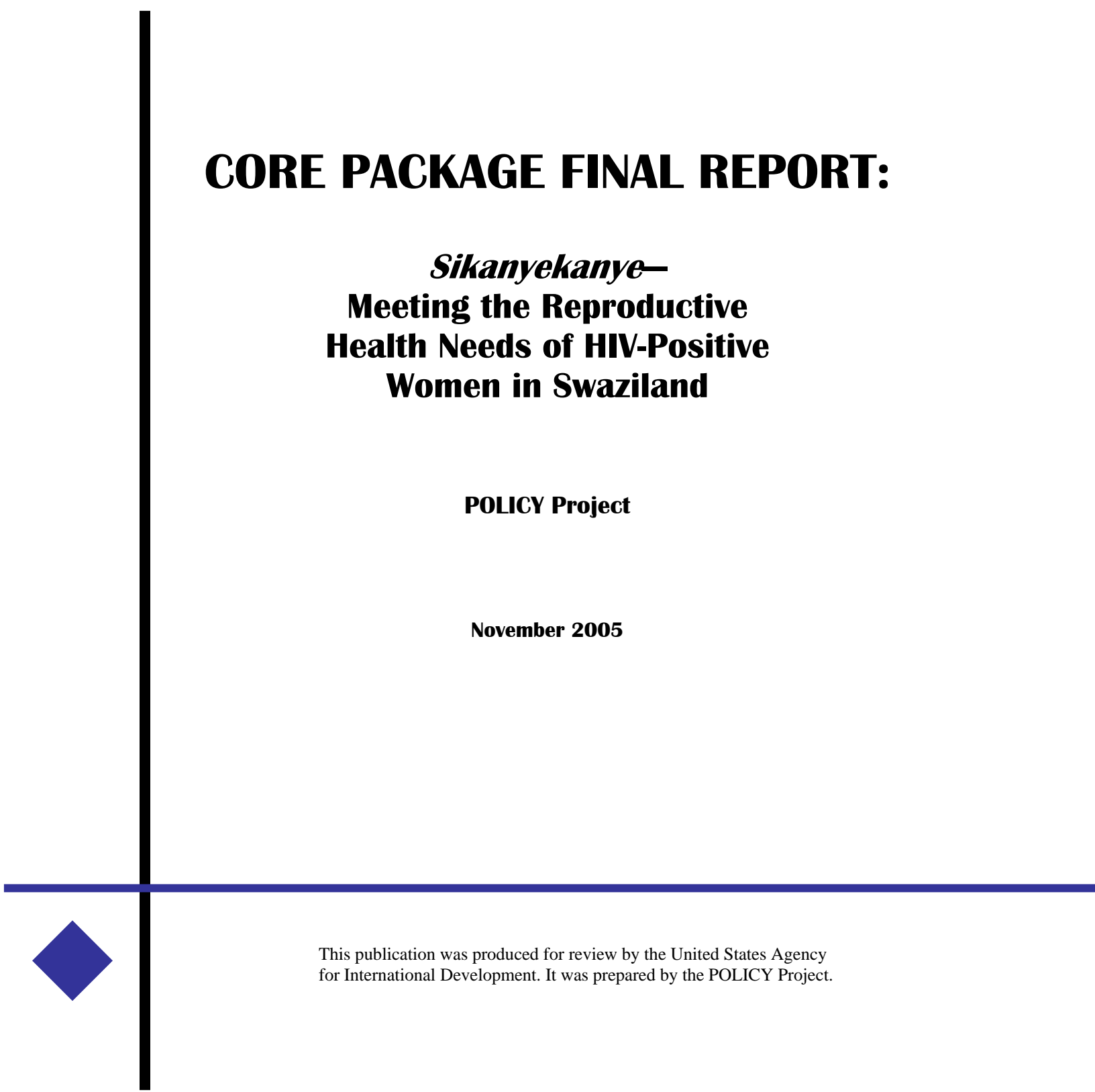
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CORE PACKAGE FINAL REPORT:

***Sikanyekanye—* Meeting the Reproductive Health Needs of HIV-Positive Women in Swaziland**

POLICY Project

November 2005



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Sikanyekanye—
**Meeting the Reproductive
Health Needs of HIV-Positive
Women in Swaziland**

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Abstract

With one of the highest HIV prevalence rates in the world, Swaziland faces substantial demand for care and support by those affected by HIV/AIDS. In particular, women bear the brunt of the epidemic, as historically their unequal social and legal status has made them more vulnerable to HIV and less able to access care and support. Against this backdrop, the USAID-funded POLICY Project initiated a core package project in May 2003. Named *Sikanyekanye*, meaning “we are together,” the project sought to identify and address operational policy barriers to improving and promoting HIV-positive women’s reproductive health within the context of programs that address reproductive health, HIV/AIDS, and sexually transmitted infections (STIs). Project activities focused on voluntary counseling and testing, prevention of mother-to-child transmission, and antenatal care.

As a result of contributions from the core package, Swaziland now stands poised to advance HIV-positive women’s reproductive health within HIV prevention and care programs. These contributions include:

- Broadening political and popular support among a multisectoral, multilevel group of government, civil society, faith-based, PLHA, and community organizations;
- Facilitating the greater involvement of people living with HIV or AIDS;
- Gathering timely, relevant data on barriers to improving HIV-positive women’s reproductive healthcare; and
- Initiating policy dialogue and advocacy activities.

This report provides background information on the status of women, HIV/AIDS, and the policy environment in Swaziland. It includes a detailed description of the project approach, activities, and results, followed by implementation challenges. The report ends with an examination of the project’s impact, concluding that the advocacy and policy change strategy used in the core package provides a multisectoral and multilevel framework for advancing HIV-positive women’s reproductive health globally.



Abbreviations

ANC	antenatal care
ARV	antiretroviral
ART	antiretroviral therapy
FBO	faith-based organization
FGD	focus group discussion
FLAS	Family Life Association of Swaziland
FP	family planning
GIPA	greater involvement of people living with HIV/AIDS
GSH	Good Shepherd Hospital
ICW	International Community of Women Living with HIV/AIDS
IEC	information, education, and communication
MCH	maternal and child health
MGH	Mbabane Government Hospital
MOHSW	Swaziland Ministry of Health and Social Welfare
NERCHA	National Emergency Response Committee on HIV and AIDS in Africa
NGO	nongovernmental organization
PHU	public health unit
PLHA	people living with HIV/AIDS
PMTCT	prevention of mother-to-child transmission
PORECO	Pilot Operational Research and Community Based Project
RH	reproductive health
SASO	Swaziland AIDS Support Organization
SINAN	Swaziland Infant Nutrition Action Network
STI	sexually transmitted infection
TASC	The AIDS Information and Support Centre
TB	tuberculosis
SWAPOL	Swaziland Positive Living for Life
UNAIDS	The Joint United Nations Programme on HIV/AIDS
UNFPA	United Nations Population Fund
VCT	voluntary counseling and testing
WHO	World Health Organization



I. Introduction

Rationale for the Project

Research suggests that most HIV-positive women do not receive the information, support, referrals, and related services necessary to meet their specific reproductive health (RH) needs. Instead, HIV-positive women experience stigma and discrimination related to their sexuality and reproductive decisionmaking. HIV-positive women have often been viewed as vectors of transmission, with reproductive health information focused exclusively on protecting the unborn child. Also, providers have often made implicit and explicit recommendations that HIV-positive women should not engage in sexual relations or make choices about childbearing, especially the desire to have a child (ICW, 2002). Furthermore, although little data exist specific to HIV-positive young women's experiences, available information suggests that HIV-positive young women may experience even harsher sanctions.¹ As with stigma and discrimination more broadly, fear of coercion regarding reproductive decisionmaking appears to be a reason why women do not seek out voluntary counseling and testing (VCT) in the first place (ICRW, 2002).

In 2003, POLICY initiated a core package in Swaziland to address HIV-positive women's reproductive health issues, as Swaziland has one of the highest HIV prevalence rates in the world. The Swaziland core package objectives were to

- Assess and document barriers and gaps to promoting HIV-positive women's reproductive health in Swaziland, especially in the context of VCT, prevention of mother-to-child transmission (PMTCT), and antenatal care (ANC) programs;
- Strengthen the capacity of people living with HIV or AIDS (PLHA) organizations—focusing on HIV-positive women-run groups—to implement advocacy activities to promote HIV-positive women's reproductive health and to reduce stigma and discrimination; and
- Strengthen reproductive health and HIV care policies and guidelines—especially in the context of VCT and PMTCT programs—to better promote HIV-positive women's reproductive health and to reduce stigma and discrimination.

To accomplish these objectives, key stages of the Swaziland core package process included the following:

- Identifying Swazi project partners and supporting collaborative planning—including the establishment of a multisectoral coordinating committee—and sensitization of important stakeholders;

¹ Two publications on the needs of HIV-positive people note the absence of young PLHA views in the assessment of reproductive health needs (ICW, 2002 and Jere, 2002). Also, the proceedings from the recent series of Young Women's Dialogues held by ICW in Southern Africa highlight that HIV-positive young women's perspectives and needs, especially related to their reproductive health, have been absent from policy dialogue and programming decisions.

- Conducting an in-depth analysis of the current situation of HIV-positive women's reproductive health and its links to components of VCT and PMTCT programs;
- Undertaking policy dialogue and advocacy activities to review information and access current service availability and to prioritize interventions to be included in VCT, PMTCT, and other RH programs in the *Swaziland National Strategic Plan for HIV/AIDS 2000–2005* and the *National Reproductive Health Strategy/Plan of Action 2002–2006*; and
- Developing and implementing a multilevel advocacy and training strategy to mobilize support for improved reproductive health of HIV-positive women.

The project initially planned to complete all four stages outlined above; however, because the assessment phase took more time than anticipated, only preliminary policy dialogue and advocacy activities were initiated. Further policy dialogue and advocacy activities were included as follow-up work subsequent to the core package's conclusion.



Background Information

Women and HIV/AIDS

Swaziland's 1.1 million people have been especially hard hit by HIV/AIDS. This Southern African country has one of the highest HIV prevalence rates in the world, at 38.8 percent (UNAIDS, UNICEF, and WHO, 2004). Like most other African countries, young women are particularly vulnerable to HIV in Swaziland, with prevalence rates at 47.7 percent among women ages 25–29 (Whiteside et al., 2003). A national survey of women attending antenatal clinics in 2002 shows an HIV prevalence of 38.6 percent among women who attended clinics (Whiteside et al., 2003). The 2002 survey data show little difference in HIV prevalence between rural and urban areas, at 35 and 40.6 percent respectively (Whiteside et al., 2003).

Women's Status and Rights

Even though women constitute the majority of Swaziland's population, few women occupy political decisionmaking positions (United Nations Country Team (UNDP), 2003). As a result, policies fail to adequately reflect or address women's interests and needs. Moreover, until recently the constitution stated that women were minors. Although the constitution was recently changed to grant women equal status to men, cultural norms and other laws continue to reinforce women's lesser status. For example, existing laws still restrict women's access to and control over vital resources. According to the traditional Swazi *kukhonta* system, a woman cannot hold land.

Such social and legal inequalities reinforce gender-based constraints faced by Swazi women in their relations with their husbands and families. Swazi women answer to male figures in the family, such as the father, husband, or brother-in-law, and this control affects women's reproductive health. Many women who want to practice family planning are inhibited by their spouse's lack of support. The Family Life Association of Swaziland (FLAS) found in a 1999 study that "many men in rural areas have the attitude that modern contraception is a foreign intrusion that does not integrate well with traditional practices. They also believe that it kills."² Moreover, many women must ask for their husband's consent to obtain a prescription for family planning methods. Finally, some women fear seeking medical assistance because they do not wish to draw attention to themselves, particularly if their spouses or family members see their actions as challenging traditional custom.³

Policy Environment

Swaziland is a signatory to international conventions and party to declarations related to promoting reproductive health. Most recently, as a party to the Windhoek Declaration of February 2005, Swaziland recognized that reproductive health is an essential component

² POLICY Project communication with FLAS, April 2003.

³ POLICY Project communication with partners, April 2003.

of health and human rights and has committed to promoting, strengthening, and implementing RH policies to improve its citizens' reproductive health. In addition, Swaziland subscribes to international conventions and declarations that validate and encourage the greater involvement of people living with HIV or AIDS (GIPA). Swaziland was a participant at the United Nations General Assembly Special Session on HIV/AIDS in 2001, thereby expressing support for the Declaration of Commitment on HIV/AIDS and the Abuja Declaration on HIV/AIDS, Tuberculosis, and Other Related Infectious Diseases—both of which promote the GIPA principle.

Although Swaziland has made these commitments, they have yet to become operational through the implementation of national policies and strategies. When the project started in May 2003, there were no coordinated strategies designed to promote HIV-positive women's reproductive health or to reduce stigma and discrimination experienced within their families or the healthcare sector. For example, although Swaziland's *National HIV/AIDS Strategic Plan for 2000–2005* stated that women have increased chances of acquiring HIV, it did not include specific information on HIV-positive women's reproductive health. Additionally, the information was not articulated in relevant VCT, PMTCT, and ANC policies and guidelines. Lastly, consultation with stakeholders, including PLHA organizations, indicated that HIV-positive women and their concerns have been largely absent from policy dialogue and resulting decisionmaking.

At the time *Sikanyekanye* began, the Swazi National Emergency Response Committee on HIV and AIDS in Africa (NERCHA) had recognized the gaps in responding to HIV-positive women's reproductive health and had made revising the HIV/AIDS strategic plan to include HIV-positive women and their RH needs a high priority. Initiated in this policy environment, *Sikanyekanye* was designed to supplement, support, and build on existing work outlined in Swaziland's *National HIV/AIDS Strategic Plan for 2000–2005* to explicitly address how to promote HIV-positive women's reproductive health and to reduce stigma and discrimination faced by HIV-positive women.



Project Approach: An Innovative Method of Broadening Support

Sikanyekanye's broad approach coupled up-to-date, targeted information with efforts to broaden political and popular support for the improvement of HIV-positive women's reproductive health. Using this approach, the *Sikanyekanye* project broke new ground in identifying and fostering collaboration among a range of key stakeholders not previously involved in the advocacy efforts.

Facilitating high-level, multisectoral ownership. *Sikanyekanye* focused on broadening policy dialogue by fostering multisectoral ownership of the project and process. This focus was evident from the beginning of the project, with the formation of a multisectoral coordinating committee in July 2003 by POLICY and partners, including the Ministry of Health and Social Welfare (MOHSW), the U.S. Embassy/Swaziland, the Swaziland Infant Nutrition Action Network (SINAN), and NERCHA. This committee was made responsible for developing coordination, consensus, and commitment to identifying and responding to HIV-positive women's RH needs. Members included government leaders; project implementers; national NGOs; and PLHA support groups such as the Swaziland AIDS Support Organization (SASO), Women Together, and the Swaziland Positive Living for Life (SWAPOL). The chair was the Deputy Director of Health Services of the MOHSW. The committee named itself and the project *Sikanyekanye*, meaning "we are together." Members met monthly to continue the design, implementation, and support of all project activities.

Promoting the greater involvement of women living with HIV/AIDS. The GIPA principle was an important focal point of *Sikanyekanye*. When the project started, PLHAs were largely excluded from policy and decisionmaking processes; this was especially true for women. By design, the project grounded itself in participatory processes intended to identify, prioritize, advocate for, and develop policy solutions with the meaningful involvement of PLHAs. Notably, an intergroup coordinating committee was formed and included PLHAs, particularly women. As a result, significant involvement and leadership by HIV-positive women occurred in all phases of the project.

Engaging leaders at the community level. Initial consultations to establish the project identified the critical role that community leaders play in shaping HIV-positive women's access to reproductive healthcare and support. *Sikanyekanye* understood that to improve HIV-positive women's access to reproductive healthcare in their day-to-day lives, it would be essential to identify barriers and opportunities for change not just within the formal health sectors but also within other sectors and organizations that in many cases exert equal or greater influence on HIV-positive women's reproductive health. For example, *Sikanyekanye* adopted a strategic, structured approach that engaged a range of leaders in the local community—businesses, faith-based organizations, traditional leaders, men, and mothers-in-law—in the implementation of each project activity. Furthermore, *Sikanyekanye* made a deliberate effort to involve other leaders and stakeholders who had not been previously involved as stakeholders in promoting HIV-positive women's reproductive health.

Strengthening the multisectoral, multilevel support necessary to promote HIV-positive women's reproductive health. To capitalize on the diversity of the coordinating committee members, the project integrated capacity building and advocacy throughout the project, understanding that support for change is necessary at every level. This approach empowered committee members, created opportunities for PLHAs to speak up, and raised awareness of HIV-positive women's RH issues in the community. Ultimately, the project's leadership and its activities were structured so that all levels of leadership were fully engaged (see Box 1).

Box 1. Key Stakeholders

- Government officials
- National NGOs
- PLHA organizations
- Women living with HIV/AIDS
- Businesses
- Faith-based organizations
- Traditional leaders
- Men
- Mothers-in-law



Project Activities

The *Sikanyekanye* coordinating committee and its leadership structure guided and informed all project activities. Specific activities are described below.

Formation of *Sikanyekanye* Coordinating Committee

Summer 2003

The project initiated its activities by forging partnerships with organizations that were interested in working on improving and promoting HIV-positive women's RH needs. Participants maintained this level of cooperation throughout the project's life by holding regular coordinating committee meetings to design various project components, gain consensus on strategies and tasks, and plan next steps for achieving its goals.

Broadening Popular Support: Awareness-raising at Multiple Levels

March 2004 launch, ongoing activity

Throughout the project's life, the *Sikanyekanye* team sought to broaden political and popular support, especially by initiating dialogue and promoting greater visibility of HIV-positive women's reproductive health as a central health issue for Swaziland. The team built increased support by encouraging high-level officials to speak out in favor of the project and by getting media coverage of this high-level endorsement. It also mobilized peer-to-peer support for HIV-positive women's reproductive healthcare by engaging coordinating committee members to raise awareness with their constituencies.

In building this high-level support, the coordinating committee publicly launched *Sikanyekanye* in conjunction with International Women's Day on March 5, 2004. The launch consisted of a project description and speeches on HIV-positive women's RH needs and on the importance of community mobilization. The event garnered extensive media coverage, including a headline announcing, "HIV-positive Women Can Still Love or Have Children." In addition, the U.S. Ambassador, the Principal Secretary of the MOHSW, and others demonstrated their political commitment to addressing the issue through policy change. Their speeches emphasized that meeting women's RH needs and involving men in the reduction of stigma are crucial to achieving Swaziland's broader health policy goals. In the words of the Principal Secretary of the MOHSW, Dr. Kunene:

*Our efforts to foster awareness on the sexual and reproductive health rights of women must therefore take cognizance of male involvement so as not to leave any gaps in the knowledge of both ... This project comes at the right time, as research findings from *Sikanyekanye* [core package] can be integrated with other ongoing PMTCT and sexual and reproductive health initiatives.*

As coordinating committee members carried out project research and further dialogue with their constituencies, they continued to increase the opportunity for public dialogue

and popular support for HIV-positive women's reproductive health. In particular, leaders at different levels engaged in awareness raising through their assessments with constituencies. As part of the assessment process, leaders facilitated dialogue to identify actions that constituents (i.e., healthcare providers in VCT, PMTCT, and ANC settings; businesses; FBOs; traditional leaders; men; and mothers-in-laws) could take to best promote HIV-positive women's reproductive health and to identify the support necessary to carry out these actions. All participants reported that the assessment process provided the first opportunity to openly discuss HIV-positive women's reproductive healthcare and the important steps they could take to better support it.

Participatory Assessment of Operational Policy Barriers

March–May 2004

After the launch, the coordinating committee began to focus on a primary objective of the project: assessing the current barriers and gaps to HIV-positive women's access to RH information and services in the context of VCT and PMTCT programs. *Sikanyekanye* formed a task team to conduct the research.

Assessment process. Ensuring that capacity building occurred during each project phase, research task team members were trained, and armed with their new skills, the team collected data through in-depth interviews with key informants (such as health providers and HIV-positive women) and focus group discussions (FGDs) with women living with HIV/AIDS, community members, men, and traditional leaders (see Box 2). The research team divided up so that each group interviewed their constituents—traditional leaders interviewed traditional leaders, PLHAs interviewed PLHAs, and so on. Additionally, the team reviewed current Swaziland government RH policies and strategies to compare them with real life experiences.

Box 2. List of Interviewees by Study Site		
Interviewees	Setting/Category	Institutions/Sites Included in Sample
Health providers	Health facilities	Mbabane Government Hospital (MGH) VCT Centre, Good Shepherd Hospital (GSH), public health unit (PHU), Lobamba and Motjane clinics, Family Life Association of Swaziland (FLAS), The AIDS Information and Support Centre (TASC)
Program coordinators	Workplace settings	Umbutfo Swaziland Defense Force, Correctional Services, Standard Bank (Swaziland), Malkerns Canning Factory
MOHSW representatives and UN program officers	Policymakers	MOHSW, UNAIDS, UNFPA, WHO
Trainers/lecturers	Nurse training schools	University of Swaziland, GSH, Nazarene, MGH, PHU
Church leaders (FGD)	Churches	NERCHA, Bethal (Shembe religion), Lobamba
FGDs for HIV-positive women and men	ART program clients	ART Center, Pilot Operational Research and Community Based Project (PORECO) Clinic, Lobamba Clinic
FGDs for traditional leaders, traditional healers, elderly women, women of childbearing age and youth	Support structures at family and community levels	Motshane clinic, Lobamba Inkhundla
PLHAs	Support group	Lobamba Clinic, GSH, TASC

Key assessment findings. Analysis of *Sikanyekanye*'s interview data, supplemented with the project's review of current Swazi government policies and strategies related to HIV-positive women's reproductive health, resulted in many key findings. An abbreviated list of these findings is below (see Annex A for a full summary).

- **HIV-positive women's experiences and perceptions regarding reproductive health and their partners:**
 - More than 50 percent of surveyed women had to seek consent from their partners to visit healthcare facilities.
 - Some women reported that male partners refused to wear condoms.
- **Types, nature, and roles of community support structures such as support groups, elderly women, and their partners:**
 - Many HIV-positive women did not disclose their HIV status because of the HIV/AIDS-related stigma and discrimination they faced in the community and in the family.

- Although some men involved in the FGDs expressed willingness to help and support their partners if they were HIV positive, they cited a lack of knowledge on the needs of HIV-positive women and HIV/AIDS in general.
- **Availability, use, and quality of family planning and other services (including antenatal, delivery, and postnatal care) provided to HIV-positive women:**
 - Over 70 percent of the HIV-positive women indicated experiencing RH problems recently, including genital warts and ulcers and vaginal discharge.
 - Ninety percent of the study participants had heard about antiretrovirals (ARVs) for PMTCT, but only 60 percent were using ARVs.⁴
 - Health workers cited a severe shortage of health personnel in service delivery and relevant training fields. At the same time, there was an increasing client demand for care and support.
 - Providers felt that they were unable to provide HIV-positive women with support for mental health problems such as anxiety and depression.
- **Links between reproductive health in government policies, strategies, and practice:**
 - Even though the MOHSW introduced the national PMTCT program in 2003, only 64 percent of the women had heard of the program.
 - Although women, community leaders, family members, and providers need specific information and support to promote HIV-positive women's reproductive health, national policies and strategies do not provide any related explicit guidance.

From Assessment to Action: Advocacy Strategy Development and Initial Implementation

November/December 2004

Sikanyekanye's structure promoted action from the start, particularly with its emphasis on building support through the coordinating committee's leadership across sectors and at multiple levels and with its conscious effort to link awareness raising and dialogue with assessment activities. However, the project's ultimate goal was to foster advocacy and policy dialogue to encourage policy changes that would better support positive women's reproductive health. Specific advocacy efforts included the following:

Development of a multisectoral, multilevel advocacy strategy. Once the research was completed (June 2004), the coordinating committee analyzed the findings and planned the best way forward to implement policy change. The group then formulated advocacy and policy change recommendations based on how different sectors at different levels could be involved in promoting HIV-positive women's reproductive health. (For details, see Annex B. A Multisectoral, Multilevel Advocacy Strategy: Key Recommendations to Promote HIV-positive Women's Reproductive Health in Swaziland).

⁴ ARVs are provided as part of the VCT process as needed.

Advocacy capacity building. Assessment findings showed that people in Swaziland were not aware of the reproductive health needs of HIV-positive women. In response, *Sikanyekanye* developed a strategy to increase awareness by planning advocacy capacity building with each of the main leadership structures/actors involved in the coordinating committee and assessment process. However, although several sector-specific advocacy training sessions, (for positive women, men, mothers-in-law, policymakers, and donors, business, and service providers) were planned, only one was completed. Held in October 2004, the training consisted of 21 participants, including HIV-positive women and those working at related organizations. POLICY staff, *Sikanyekanye* members, and affiliates of the International Community of Women Living with HIV/AIDS (ICW) conducted the training. The objectives were as follows:

- To explore the concept of advocacy and provide participants with an understanding of the steps required in planning an advocacy campaign aimed at strengthening a sectoral response to HIV/AIDS;
- To strengthen advocacy skills as well as provide participants with an opportunity to work on their own in-house advocacy campaigns; and
- To explore networking and collaboration as strategies essential in HIV/AIDS advocacy campaigns.

National policy dialogue. As the assessment findings confirmed, national health policies and plans did not explicitly recognize or address HIV-positive women's reproductive health or the necessary related support and programming for HIV-positive women, male partners, communities, and service providers to promote their reproductive health. In this context, as the advocacy strategy details (see Annex B), several national policies and strategies were identified for dialogue and potential strengthening.

Within the timeframe of the *Sikanyekanye* project, policy dialogue on mental health was initiated. In particular, the list of recommendations on meeting the RH needs of HIV-positive women was presented to the MOHSW in October 2004. One of the recommendations called for giving priority to mental health services for women and others infected or affected by HIV/AIDS. The MOHSW was interested in pursuing this, and as a result, a consultative meeting was held in November 2004 for 28 people from several sectors, including people working in mental health and HIV/AIDS. The meeting was successful in reaffirming the general importance of mental health and specifically addressing it within the context of HIV/AIDS-related initiatives. A Mental Health Task Team was proposed to facilitate the planning and implementation of follow-up HIV and mental health initiatives. In addition, a second meeting to strengthen political support of the Mental Health and HIV/AIDS Initiative was held at the end of the month. After these meetings, the MOHSW renewed its commitment to push the current draft of a National Mental Health Policy through Parliament for adoption.

Subsequent to the core package's completion, policy dialogue activities were initiated to discuss explicitly integrating HIV-positive women's reproductive healthcare into the *National Reproductive Health Strategy/Plan of Action 2002–2006*.

Dissemination

The *Sikanyekanye* methodology for forming a task force representing a full range of stakeholders can be used elsewhere to facilitate effective advocacy and policy change to promote HIV-positive women's reproductive healthcare. The multisectoral, multilevel advocacy strategy also provides a promising framework that can be adapted and used in other country and regional contexts. To share this methodology and process, the project presented its approach and lessons learned at a poster presentation session at the International AIDS Conference in Bangkok in summer 2004 and at a roundtable discussion at a health and human rights conference, titled "Lessons Learned from Rights' Based Approaches to Health," in spring 2005.

Laying Groundwork for the Future: Collaboration with ICW and Further Policy Dialogue

Following the core package's conclusion, *Sikanyekanye* continues to work to promote HIV-positive women's reproductive healthcare. One activity includes collaboration with ICW to foster the meaningful involvement of women living with HIV/AIDS. The two groups will work together, with ICW taking the lead, in strengthening HIV-positive women's advocacy skills to initiate policy dialogue. With other core-funded POLICY support, *Sikanyekanye* will also conduct a policy analysis of the *National Reproductive Health Strategy/Plan of Action 2002–2006*, which has not yet been adopted. This level of analysis will lay the groundwork for revising the strategic plan to include explicit strategies to promote HIV-positive women's reproductive health and ensure access to services.



Outcomes

Increased Political and Popular Support

Sikanyekanye was successful in gaining and increasing political and popular support. Before the project's inception, there had been no dialogue focused on HIV-positive women's reproductive health in Swaziland. *Sikanyekanye*'s holistic, multilevel framework and its facilitation of a committee that embodied this framework were central to putting HIV-positive women's reproductive healthcare on agendas for action at many different policy and decisionmaking levels. By engaging various sectors and leaders at all levels, *Sikanyekanye* created multiple opportunities for discussing HIV-positive women's reproductive healthcare and advocating for change.

- **High-level support.** At the project's inception in 2003, government officials were willing to voice their support of HIV-positive women's reproductive healthcare as a priority issue for Swaziland. This helped spark widespread attention and discussions about the issues; a newspaper headline read, "HIV-positive Women Can Still Love or Have Children." In addition, a policymaker recognized and validated *Sikanyekanye*'s framework by calling for a coordinated response to mitigate HIV/AIDS. Gaining this level of institutional support enabled *Sikanyekanye* to move forward with the government's support. Task team members also report that policy discussions of both reproductive health and HIV now consistently include HIV-positive women's RH needs, as evidenced by the MOHSW's commitment to reviewing the *National Sexual and Reproductive Health Strategy/Plan of Action 2002–2006* in light of HIV-positive women's reproductive health.
- **Support at community leadership levels.** The formation of the coordinating committee and its approach to promoting dialogue throughout the research and analysis processes created opportunities to discuss and build support for HIV-positive women's reproductive health at many different levels, rather than solely at the policy level. This approach opened avenues for HIV-positive women to access information and advocate for their reproductive health needs, for men to be more open and supportive of HIV-positive women and their reproductive health, for religious and traditional leaders to encourage change in the community, and for healthcare providers to address how to better serve HIV-positive women.

Strengthened Involvement of People Living with HIV/AIDS, Especially Women

Sikanyekanye affirmed that HIV-positive women must be centrally involved in shaping policy dialogue and decisions. *Sikanyekanye* members report that prior to the project, not only had HIV-positive women's RH issues not been on any policy agenda, but PLHAs did not have a place within a decisionmaking forum. Through the *Sikanyekanye* coordinating committee and project process, government officials, community leader, and

women living with HIV/AIDS collaborated in devising advocacy and policy reform strategies designed to promote HIV-positive women's reproductive health. Because of their efforts, leadership by and for HIV-positive women is now seen as vital.

Commitment to Policy Dialogue and Review of National Policies

As a result of consultative meetings and the combination of broadened political and popular support and the effective use of timely, useful information and research, the MOHSW renewed its commitment to push the current draft of a National Mental Health Policy through Parliament for adoption. Moreover, the MOHSW has also committed to having further policy dialogue on reproductive healthcare and revising the National Swaziland Reproductive Health Policy and strategic plan.

A Promising Approach to Build Support for HIV-Positive Women's Reproductive Health

Sikanyekanye promoted the participation of PLHAs and leaders at multiple levels in the design, planning, and implementation of the project. In particular, *Sikanyekanye's* leadership and participation was crucial in formulating a project approach—and eventually an advocacy and policy reform strategy—that promotes HIV-positive women's reproductive health in everyday life and in policy formulation. The focus on high-level actors and reform of related national policies and programs was crucial to providing an expansive, enabling policy framework in the government health sector. At the same time, community leader involvement was equally or more important in promoting HIV-positive women's access to reproductive healthcare, as well as reducing the stigma and discrimination faced by HIV-positive women. *Sikanyekanye* deliberately included traditional community leaders and members; involving these groups was particularly important in the Swazi context, as groups such as men and mothers-in-law maintain a significant amount of power in women's lives. This multilevel, multisectoral model could be used by other countries that want to build active support for HIV-positive women's reproductive health needs in the community and at the policy level.

Multisectoral Advocacy Strategy Recommendations

Sikanyekanye's research findings were a substantial contribution to Swaziland's policy arena. Just as or more important, the leadership structure also prepared advocacy recommendations targeted to policymakers not traditionally included in efforts to promote HIV-positive women's reproductive healthcare. Focusing on a variety of sectors, these recommendations reinforced the message that all relevant stakeholders must be involved to ensure that HIV-positive women's reproductive health needs are addressed (see Annex B). The recommendations also offer an advocacy model that other countries may want to consider.



Implementation Challenges

Political Environment and Culture

Sikanyekanye was confronted with a particular challenge—working within a conservative culture and political environment on issues affecting women who do not have a high status in the community. The project negotiated this environment successfully, beginning with bringing together stakeholders who recognized the importance of the issues. Then, *Sikanyekanye* expanded support by forming a coordinating committee whose membership included community leaders and sectors more commonly involved in reproductive health policymaking.

Processes Designed to Build Ownership Require Considerable Investment of Time

Building support and laying groundwork for such collaboration required a substantial amount of time, as forming connections is a slow process. The project took six months to convene the task force. In addition, continuing to foster and expand this network, while completing other project tasks, required a well-managed investment of time.

Moreover, the collaborative research process took longer than previously anticipated, as it had to start with capacity building to train the researchers. Although this process contributed substantially to building crucial support at multiple levels for HIV-positive women's reproductive health and resulted in an advocacy strategy that reflects the crucial role all leaders must play, it also took considerable time to complete. Thus, by the time the assessment phase was completed, the advocacy phase that would be focused on policy change could not be fully implemented during the project timeframe.

For these reasons, *Sikanyekanye* did not complete all its planned activities in a one year-time period. However, the additional time and resources invested in phases one and two, particularly the work to build support, appears to have laid a foundation to facilitate the achievement of a more comprehensive, sustainable set of advocacy and policy changes as a result of participatory, multilevel engagement.



Long-lasting Impact

Although the duration of the project was brief, *Sikanyekanye* successfully used a methodology that incorporated a multisectoral, multilevel approach to reduce stigma and discrimination, support HIV-positive women's health, and promote HIV-positive women's leadership.

At the national level, as a result of the project coordinating committee's work, a structure now exists to build and implement a coordinated policy response that promotes and protects the RH needs of HIV-positive women in Swaziland. HIV-positive women have assumed a central role within the coordinating committee and research task teams, thus increasing their ability to shape programs and policies that better meet their needs. Furthermore, the launch of *Sikanyekanye*, the media coverage, and strengthened political commitment have begun to raise the priority and awareness of HIV-positive women's RH needs in everyday discourse and policy formation. With the completion of the research and related policy dialogue and development activities, Swaziland is on the road to achieving both a policy environment and policy framework that increases positive RH outcomes and addresses related stigma and discrimination facing HIV-positive women. This is evident not only in the MOHSW's willingness to address recommendations advocating the adoption of the Mental Health Policy, but also in its commitment to review the RH strategic plan in light of HIV-positive women's needs.

Sikanyekanye has generated promising approaches and models that may be adapted and applied in other national and regional contexts. In particular, the project designed an advocacy and policy reform strategy that can serve as a model multisectoral and multilevel framework for advancing HIV-positive women's health. The core package's strategy and method focused on building multisectoral, multilevel support and greater involvement of PLHAs in all phases of the project from planning and analysis to advocacy strategy development and policy dialogue.



Annexes

Annex A.

Summary Results from Assessing Barriers to Addressing HIV-Positive Women's Reproductive Health

1. HIV-positive women's experiences and perceptions regarding reproductive healthcare provided to them.

- Over 70 percent of the HIV-positive women interviewed indicated experiencing RH problems recently, including genital itching, genital warts and ulcers, and vaginal discharge.
- More than 50 percent of surveyed women had to seek consent from their partners to visit healthcare facilities.
- Women of childbearing age in the study were generally well-informed about issues related to reproductive health and HIV/AIDS. However, elderly women's knowledge of these issues was limited.
- Some women reported that male partners refused to wear condoms.
- Women reported that their financial dependency prevented them from asserting themselves.
- Possible sources of support for HIV-positive women were primarily their partners, their families, formal and informal health providers, and the community as a whole.
- Despite the need for women to reveal their status in order to receive support, many HIV-positive women did not disclose their status because of HIV/AIDS-related stigma and discrimination from the family and community.
- Results indicated that if certain family members' attitudes and perceptions were more supportive of HIV-positive women (most notably those of mothers-in-law), then the family's attitude toward these HIV-positive women would also improve.
- Community support was mainly received through support groups initiated by PLHAs, although the number of these support groups was limited.

2. Availability, use, and quality of family planning and other services (including antenatal, delivery, and postnatal care) provided to HIV-positive women.

- Ninety percent of the participants had heard about ARVs, but only 60 percent were enrolled in the ART program.
- Routine obstetric care was often carried out by nurse midwives. Group and individual health education sessions on VCT and PMTCT were also carried out by nurse midwives.
- Women receiving ANC received group health education sessions on different public health topics such as HIV/AIDS, tuberculosis (TB), and STIs, among others. In addition, print material was distributed to the women.
- For the most part, information given to women in health facilities was not received by their partners.
- Many men preferred to receive information on sexual health from other men, traditional leaders and/or other male elders, or male healthcare providers.

- At one health facility, 50 percent of those tested for HIV returned for their results.
- At the time of the study, there were no peer support groups at VCT or PMTCT sites.
- Health workers cited a severe shortage of health personnel in service delivery and relevant training fields. At the same time, there was an increasing client demand for care and support.
- Providers felt ill-equipped to provide HIV-positive women with support for mental health problems such as anxiety and depression.
- Observations of all study sites revealed that the facilities did not have enough room for counseling.

3. Types, nature, and roles of community support structures such as support groups, elderly women, and their partners.

- The possible sources of support for HIV-positive women were primarily their partners, their families, formal and informal health providers, and the community as a whole.
- Many HIV-positive women did not disclose their status because of HIV/AIDS related stigma and discrimination in the community and in the family.
- Although some men who were involved in the focus group discussions expressed willingness to help and support their partners if they were HIV positive, they cited a lack of knowledge on the needs of HIV-positive women and on HIV/AIDS in general.
- Results indicated that if the perceptions and attitudes of mothers-in-law toward their HIV-positive daughters-in-law are changed, the family's attitude toward these HIV-positive women would also improve.
- Many HIV-positive women in relationships needed to obtain consent from their partners or in-laws to seek VCT services, maternity care, or in choosing whether to breastfeed their infants or to use infant formula. They would even need consent from a family member to receive treatment for AIDS.
- Community support was mainly received through support groups initiated by PLHAs. There were complaints, however, that these support groups had no capacity for project management, project formulation, and financial sustainability.
- FGDs with FBOs agreed that HIV-positive women should be provided with both spiritual and material support.

4. Links between reproductive health in government policies, strategies, and practice.

- Even though the MOHSW introduced the national PMTCT program in 2003, only 64 percent of the women had heard of the program.
- Data from the National PMTCT Strategic Plan 2003 indicates that 73 percent of women who attended a clinic received counseling and 54 percent of those counseled tested for HIV. The strategic plan cites the lack of emphasis on community preparedness, participation, and mobilization as a reason for poor uptake of VCT; so far, assessment findings indicate that this issue has yet to be addressed.

- Although increasing male involvement is a priority in the *National Reproductive Health Strategy/Plan of Action 2002–2006*, many providers and men lack the knowledge and skills to support HIV-positive women’s reproductive health.
- The *National Reproductive Health Strategy/Plan of Action 2002–2006*, *PMTCT Guidelines 2003*, and *MOHSW Health Sector Response to HIV/AIDS in Swaziland 2003–2005* outline the importance of community involvement, strengthening PLHA organizations and support groups, and the need for public/private sector collaboration in providing support for HIV-positive women. Assessment findings concur in the importance of these approaches, but find them lacking in practice.
- Several of MOHSW’s policies, including the *National Reproductive Health Strategy/Plan of Action 2002–2006*, *PMTCT Guidelines 2003*, and the *MOHSW Health Sector Response to HIV/AIDS in Swaziland 2003–2005* include addressing human capacity needs such as provider training, building partnerships with the public and private sectors, improving gaps in reproductive health service delivery, filling vacant posts and developing staff retention policies, and integrating PMTCT into reproductive health and maternal and child health services. The assessment findings concur that these actions are critical to promoting HIV-positive women’s reproductive health; however, most have not been implemented.
- Although women, community leaders, family members and providers need specific information and support to promote HIV-positive women’s reproductive health, national policies and strategies do not provide any related explicit guidance.

Annex B.

A Multisectoral, Multilevel Advocacy Strategy: Key Recommendations to Promote HIV-positive Women's Reproductive Health in Swaziland

1. Ensure that the health sector's structure can meet the needs of HIV-positive women by

- Integrating HIV/AIDS education; education related to RH behaviors and decisionmaking; and family planning, VCT and STI management into reproductive health programs throughout the public and private sector and empowering family planning staff to diagnose, treat, and manage STIs so there is comprehensive care available and accessible to women, particularly HIV-positive women.
- Developing a comprehensive RH and HIV/AIDS curriculum for all health training institutions.
- Expanding and providing continued training of all healthcare providers in syndromic management of STIs.
- Setting up mobile VCT services to reach more people in the community.
- Using rapid tests at VCT facilities to avoid the low return rate for results.
- Integrating PMTCT into maternal and child health services.
- Improving of service infrastructure and capacity to allow for private and confidential counseling at healthcare facilities.
- Implementing programs for meeting the RH needs of HIV-positive women in the conventional health system and ensuring they are understood and supported at the highest political level.
- Ensuring that youth-friendly RH programs are available and accessible.
- Improving the management of mental disorders (such as anxiety and depression) experienced by HIV-positive women by ensuring adequate counseling and the provision of information on functional support groups at all VCT sites.
- Developing strategies to address human capacity needs for delivering health services, including increasing the number of male nurses trained to facilitate greater male involvement and increased uptake in services, including VCT; as well as meeting the needs of men.

2. Strengthen support for HIV-positive women and eliminate stigma and discrimination by

- Increasing male involvement through advocacy and awareness campaigns to enhance the uptake of programs that provide care and support for HIV-positive women.
- Encouraging and assisting FBOs and traditional leaders to set up advocacy and awareness campaigns on reproductive health, to carry out health programs, and to incorporate HIV/AIDS education, counseling, support, and care in existing community outreach services.
- Establishing additional support groups and strengthening the capacity of existing support groups by providing technical assistance and financial support.
- Providing awareness-raising information for elderly women, given the influential role that elderly women play in the Swazi community. Addressing this

fundamental need could result in the development of functional community home-based care programs, which can be led by elderly women.

- Training lay counselors, who would ensure the continuity of counseling and support to HIV-positive women.
- Providing counseling for teenage mothers and the necessary support and promotion of youth-friendly RH programs.
- Integrating support groups into PMTCT programs to ensure the social support of HIV-positive pregnant women.
- Enabling HIV-positive women and their partners to make informed choices about reproduction by providing relevant and up-to-date information on existing programs and services.
- Working with traditional leaders and the community to explore ways to build upon the positive aspects of Swazi culture, while discouraging aspects that may lead to stigma and discrimination or an increased vulnerability of women.

3. Increase education and awareness on HIV/AIDS, particularly reproductive health needs of HIV-positive women, by

- Presenting information, education, and communication (IEC) materials in SiSwati with the full participation of PLHAs and cooperation from the media.
- Involving PLHAs in the mobilization of communities around HIV/AIDS and reproductive health issues and ensuring that they play a key role in planning and carrying out advocacy campaigns.
- Increasing knowledge of and access to PMTCT services among women in the communities.
- Increasing community awareness of and improving access to ART centers.
- Increasing community awareness of adolescent reproductive healthcare needs.
- Preparing IEC materials that are “youth friendly.”
- Promoting increased access to a constant and reliable supply of male and female condoms at strategically located service delivery points.
- Developing peer support groups of HIV-positive women and informing women of support groups at FP, PMTCT, and VCT centers.

4. Initiate income-generating activities to improve the socioeconomic status of Swazi women.

5. Address confidentiality and explore how it can be improved to increase the uptake of VCT, PMTCT, and other reproductive health programs.

6. Encourage the formulation of comprehensive workplace policies and programs for HIV/AIDS, including reproductive health, among the business sector/workforce.

7. Develop guidelines and tools for conducting advocacy so specific sectors can effectively respond by addressing and advocating for RH needs.

8. Develop training curricula for health service providers. The curricula should also include guidelines on dealing with the issue of provider burnout and offering “care for the caregivers.”



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