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**Policy Reform to Meet
Access-to-Treatment Goals:
HIV-Positive Women's Access
to Care, Treatment, and
Support (ACTS) in Swaziland**

POLICY Project

March 2006

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Contents

I.	Project Background	1
II.	Resulting Analysis and Action	3
A.	Analysis: HIV-Positive Women’s Barriers to ACTS	4
A.1	Limited Access to ART and Gender Inequalities	4
A.2	Need for High-Quality, Comprehensive Care and Services	5
A.3	Knowledge and Information Tailored to Women	6
A.4	Other Access-to-Treatment Issues	8
B.	Policy Assessment Related to ACTS	9
C.	Participant Priorities and Action Plans	10
III.	Achievements	12
IV.	Lessons Learned and Implications for Future Programming	13

Policy Reform to Meet Access-to-Treatment Goals: HIV-Positive Women's Access to Care, Treatment, and Support (ACTS) in Swaziland

This report summarizes the analysis, actions, and lessons learned from the core-funded activity, *Policy Reform to Meet Access-to-Treatment Goals*. The POLICY Project, in partnership with the International Community of Women Living with HIV/AIDS (ICW) in Swaziland and South Africa, implemented the project from October 2004 to December 2005.¹ The report describes the results of the project's rapid assessment of HIV-positive women's access to care, treatment, and support (ACTS) in Swaziland. The purpose of the assessment was to gain a clear understanding of the specific issues affecting HIV-positive women and how the policy environment supports advocacy opportunities for policy and programmatic change. Subsequent to the rapid assessment, POLICY supported ICW-led validation and capacity-building workshops to translate analysis into prioritized advocacy issues and action plans. The report is organized as follows:

- Project Background
- Resulting Analysis and Action
- Achievements
- Lessons Learned and Implications for Future Programming

I. Project Background

While current global and national programs offer unprecedented opportunity to expand access to HIV/AIDS treatment, such efforts need to address women's barriers to access if the programs are to achieve their goals. As compared with HIV-positive men, HIV-positive women often face harsher stigma and greater discrimination when seeking treatment. In addition, HIV-positive women often lack the information, resources, decisionmaking power, models of care, gender-specific research results, and support needed for prioritizing their own healthcare needs. Experience shows that the active involvement of HIV-positive women at all levels of decisionmaking, including policy formulation, is essential to treatment preparedness and expanded access. Accordingly, POLICY collaborated with ICW to pilot test a set of approaches for identifying and addressing gender barriers in Swaziland with the goal of disseminating to other countries the lessons learned from those approaches. The project focused primarily on building the advocacy capacity of HIV-positive women by training them in the skills required to engage in policy dialogue and shape policy, planning, and implementation processes to ensure that HIV/AIDS treatment reaches women and addresses the specific gender-related challenges related to ACTS. The project objectives called for:

- Developing and implementing a rapid assessment to identify barriers to access to treatment and to map strategic policy opportunities;

¹ Given that initial discussions and planning with ICW for an HIV-positive women-led project were protracted, project activities did not begin until January 2005.

- Strengthening the capacity of HIV-positive women to advocate for their unique needs in accessing treatment and to shape related policies, guidelines, and plans; and
- Designing and documenting tools and approaches that promote advocacy and policy dialogue and address related policies, guidelines, and plans that respond to women's access-to-treatment needs.

Activities. To take advantage of the synergies between the project's focus on HIV-positive women's barriers to access to treatment and the HIV-POP jointly funded core-funded target of opportunity, titled *Meeting the Reproductive Health Needs of HIV-Positive Women*, ICW carried out several activities simultaneously in order to address women's access to treatment and reproductive healthcare. The present report, however, focuses on women's access to treatment in Swaziland² and describes how the project:

- **Formed a multisectoral reference group** to provide strategic guidance and increase support for all phases of the project;
- **Undertook a rapid assessment of women's barriers to ACTS**, including an assessment of women's experiences, mapping of current policies and guidelines related to women's access to treatment, and identification of opportunities for change at the community, facility, and national levels in Swaziland;
- **Conducted a validation workshop** with 20 ICW members from Swaziland³ to verify the findings of the rapid assessments and to identify priority issues for advocacy;
- **Designed an advocacy capacity-building training curriculum**, created and led by HIV-positive women, on promoting HIV-positive women's ACTS;
- **Conducted an advocacy training workshop** with 20 ICW members from Swaziland⁴ to strengthen advocacy skills and prepare advocacy action plans for promoting women's ACTS;
- **Assisted HIV-positive Swazi women in implementing action plans** through ongoing mentoring, financial support, and follow-up capacity building;
- **Worked to strengthen the organizational capacity of ICW's networks** throughout the project process.

² See POLICY's *Final Report: Meeting the RH Needs of HIV-Positive Women* (January 2006) for further details about the core-funded target of opportunity, which focused on HIV-positive women's reproductive health. The activity was also carried out by ICW and included South Africa as well as Swaziland.

³ The validation and advocacy training workshops for the activity were conducted simultaneously with workshops for the reproductive health target of opportunity. As a result, the workshops included not only the 20 ICW members from Swaziland but also 23 ICW members from South Africa. Although the activity plans related to treatment were designed and implemented only in Swaziland, the combined workshops provided an important opportunity for women in South Africa to contribute their experiences to the assessment and development of action plans for treatment and to learn more about women's access-to-treatment issues.

⁴ See footnote 3.

II. Resulting Analysis and Action

Highlights of Analysis and Action. This section highlights project outcomes: an analysis of major barriers to HIV-positive women's ACTS; a brief assessment of the current policy environment related to women's access to treatment; and the prioritized advocacy issues and action plans that stemmed from the ICW-POLICY validation and advocacy workshops.

Project Framework: Women's Access to Care, Treatment, and Support. Of note, one of the project's initial accomplishments was its clarification of terms of reference with regard to access to treatment. The project's initial terms of reference focused on HIV-positive women's access to antiretroviral therapy (ART). However, consultation with ICW and its members pointed out the limitations of initiatives focused solely on the provision of and adherence to ART. HIV-positive women commented that they face a broader range of issues related to access to treatment and therefore stressed the importance a more holistic approach to treatment. Thus, the project adopted ICW's framework as follows:

Definition of ACTS⁵

ACTS refers to HIV-positive women's ability to gain consistent access to all available care, treatment, and support services, including antiretrovirals, medication for opportunistic infections, and advice and treatment for medication side effects; diagnosis of and treatment for sexual and reproductive health matters, including treatment of sexually transmitted infections (STIs); information and advice on PMTCT, healthy pregnancy, and safe motherhood; awareness, information, and treatment for gender-specific illnesses; pre- and post-test counseling, ongoing counseling, and guidance on how to obtain financial support to cover treatment or doctor's fees; home-based care and other care-in-the-community programs and initiatives; workplace policies; and supportive environments at home, in the community, workplace, place of learning, and public and health service institutions.

ICW recognizes that gender inequalities can constrain HIV-positive women's access to care, treatment, and support as well as their ability to use treatment, information, and advice to improve the quality of their lives. We also recognize that the care, treatment, and support needs of HIV-positive women differ from those of men.

Within the framework of the terms of reference, the project analysis and actions retained a specific focus on women's barriers to accessing ART but also assessed barriers to the broader care, treatment, and support issues integral to HIV-positive women's health. In discussing the barriers, workshop participants considered barriers related to the process of achieving ACTS rather than the full range of clinical issues that need to be addressed in providing comprehensive care and treatment. For example, although it is important to

⁵ Excerpted from ICW's *Positive Women Monitoring Change* (May 2005), developed as part of the ICW-Support for the International Partnership Against AIDS (SIPPA) collaboration. The document is available on ICW's website at <http://www.icw.org>.

address malaria and tuberculosis as part of comprehensive clinical care for HIV-positive women, the workshop participants did not focus on such clinical issues.

A. Analysis: HIV-Positive Women's Barriers to ACTS

Organized around four workshops, a rapid assessment process identified Swazi women's barriers to ACTS based on the experiences of 77 HIV-positive women (54 from Swaziland and 23 from South Africa). The findings include results distilled from two earlier ICW-sponsored activities held in Swaziland in 2004 and 2005: ICW's collaboration with Support for the International Partnership Against AIDS in Africa (SIPAA) and Young Women's Dialogue. Workshop participants identified the following barriers to access to care, treatment, and support for HIV-positive women as essential elements to address through ACTS advocacy efforts.

A.1 Limited Access to ART and Gender Inequalities

Decisionmaking power and financial constraints. Workshop participants commented that because of the lack of locally available services or their concerns about confidentiality, HIV-positive women must often seek healthcare services outside their communities. However, participants remarked that a lack of decisionmaking power in their relationships and families affects their ability to access HIV/AIDS treatment, especially in distant locations. Often, women must ask their partners or families for permission or funds so that they may visit health centers and purchase medication. Control over and access to funds is, thus, a particular issue for women in rural areas who are faced with relatively high travel costs in addition to significant expenses related to care and treatment, especially for medications. Note that financial constraints affect more than care and treatment for HIV/AIDS and extend to care and treatment for STIs and opportunistic infections (OIs).

Decisionmaking power is also a particular issue among young women, who are not expected to have reproductive health concerns, especially when unmarried. Often, young women must request parental or guardian consent before seeking reproductive health services. Lack of autonomy also frequently means that women of all ages are kept ignorant of their HIV status and the type of treatment they receive. For example, women reported that traditional healers had treated them, yet they had not even been informed of their HIV status.

Gender-related stigma and discrimination in the family and community. Workshop participants recounted their fear of stigma and discrimination, both of which can prevent a woman from revealing her HIV-positive status. Participants also pointed to confidentiality and disclosure concerns and noted that it is difficult for a woman to maintain an ARV (antiretroviral) treatment regimen without disclosing her status. Participants emphasized that, owing to the risk of rejection and the fear of being blamed for bringing HIV into the family, women are fearful of disclosing their status to husbands/partners and families. In addition, families may not understand or prioritize women's treatment and care needs. Where women are forced to rely on local clinics, they may choose not to access treatment for fear of being seen and thereby revealing their

status. Similarly, despite the risk of HIV transmission, HIV-positive women may choose to breastfeed infants instead of using formula. In many cultures, breastfeeding is preferable, and reliance on formula is indicative of positive HIV/AIDS status.

Violence. Workshop participants revealed that women face various forms of violence exacted by partners, including physical and sexual assault. Their experiences with violence—including the fear of violence—often prevent them from undergoing HIV testing or even acquiring their complement of treatment supplies. Women reported violence in response to disclosures of HIV-positive status and as retribution for bringing HIV into the household.

Partners' healthcare. Participants reported that partners who work some distance from the community often return home when their health fails, expecting their female partner to care for them. Participants noted that many of their partners do not seek healthcare even when they know or suspect that they are HIV-positive. Some participants said that they face an extra burden in caring for their male partners, especially when the male partner refuses to seek healthcare. In some cases, participants described situations in which their partners helped themselves to the participants' medications rather than obtaining their own. In the words of one participant, "We don't take our own treatment" because of our partners.

Burden of care. Workshop participants reported that women are often overburdened as care providers for family members and others affected by HIV/AIDS. At the same time, many of these women are themselves HIV-positive and need support. Owing to social pressures and expectations, however, women may place duty to family over their own healthcare needs. When HIV-positive women do seek medical care, they may be unable to maintain their home-based and community responsibilities. Participants also noted that the government's reliance on women to fill gaps in government services exacerbates women's care burdens. In fact, some local hospitals are increasingly insisting that a caregiver attend a patient during a hospital stay. Even though the Swazi application to the Global Fund included fees to be paid to community caregivers, women report that they have yet to receive any such stipends.

A.2 Need for High-Quality, Comprehensive Care and Services

Gender-related stigma and discrimination. Subjected to the judgmental attitudes of healthcare workers and counselors, workshop participants experienced stigma and discrimination when seeking care, treatment, and support. In the healthcare setting, such attitudes are reflected in doctors' lack of attention to and respect for HIV-positive women and their failure to take the time to explain to women the full range of treatment options. In addition, women who are not expected to be sexually active, such as young women and older widows, face a lack of care, treatment, and support services. Many participants reported that they simply did not seek care for fear of how healthcare providers would treat them. Of note, some South African participants reported in the validation workshop that at times their access to treatment programs is contingent on other factors, such as agreeing to use certain contraceptives.

Healthcare provider knowledge about treatment and women. Workshop participants concluded that healthcare providers demonstrated inadequate knowledge of HIV-positive women's needs. Service providers need up-to-date information on the impact of ART on women as compared with men and on ART's interaction with contraceptives. In some cases, HIV-positive women felt that service providers discounted their preferences for treatment.

Women-specific clinical research. Workshop participants familiar with treatment issues noted that most ART-related research focuses on men. The participants pointed out that healthcare providers need to receive training and updates on what is known and not known about ART's effects on women. Participants also highlighted the need to advocate for further research specific to women, such as how ART affects the reproductive system of younger women or interacts with contraceptives; participants also noted that advocacy is essential for other underfunded areas of research specific to women's ability to prevent HIV transmission, such as microbicides.

Other clinical services, particularly OI and reproductive health. HIV-related services are often limited to specific health centers and distribution points, such as pregnancy-related services. Given that HIV affects a range of health conditions, clinical services need to be linked, particularly services related to STIs and OIs and the prevention of HIV transmission. Participants reported a lack of treatment for OIs and noted that medical staff refuse to administer OI treatment, especially when STIs are involved.

“There is a chemical applied to warts that should not touch uninfected part and they say do it yourself.” ~Workshop participant

HIV-positive women also reported the need for Pap smears for cervical cancer screening and testing as well as the need for ongoing counseling following an HIV-positive diagnosis.

Access to nonclinical care and support services. In addition to treatment, HIV-positive women need access to other types of care and support, such as information on income-generating activities, inheritance rights, and how to obtain supplies to facilitate home-based care. Workshop participants also mentioned the need for pain management at the end of life; preparation for death through counseling and support; and family and orphan support.

A.3 Knowledge and Information Tailored to Women

Women's treatment literacy. While lack of treatment literacy is a barrier for both men and women, workshop participants highlighted the additional barriers that women face. They believed that outreach to women is a low-priority issue and, thus, few women are being reached by the limited education efforts that do exist. Furthermore, women need comprehensive information on issues with unique consequences for women, such as treatment side effects including changes in body shape and interactions of ART and oral contraceptives, as well as the importance of good nutrition, resistance and adherence to

treatment, obtaining and understanding the benefits of ARVs, and OI treatment. Yet, treatment education materials do not address women-specific treatment issues. Women living in rural areas face further difficulties in accessing information. Rural women usually do not speak English, yet much of the information currently available is written in English.

Importance of support groups. Workshop participants named peer and spiritual support as crucial to gaining information about their circumstances and providing emotional support. For many participants, support groups helped them through the difficulties of dealing with a diagnosis of and living with HIV, AIDS, or other long-term incurable illnesses, such as hepatitis C, which co-infects many HIV-positive people. They believed that HIV-positive women not linked with a support group face greater challenges, as they have less access to care, support, and information. In the context of treatment literacy, participants reported that support groups offered powerful networks for mobilizing community-based education and treatment support for women and others.

At the same time, some participants noted that, within some support groups, discrimination by age and gender translates into a lack of support and solidarity among people living with HIV and AIDS. Participants also reported an emerging lack of solidarity within support groups between people on and not on ART. In addition to resources dedicated to developing treatment literacy, participants called for efforts to strengthen support group sustainability and solidarity.

Meaningful involvement of HIV-positive women. Even though HIV-positive women can draw on their powerful experiences to craft solutions to ACTS issues, most Swazi workshop participants felt that they lacked the skills, knowledge, or confidence to participate in policy formulation.

“People in government ask us, ‘Can you formulate policies?’ and we can’t; we don’t know where to start, how we approach people, and what questions to ask”
~Workshop participant

Many participants felt that they lacked a sufficiently strong voice to enter the policymaking arena, noting that society largely ignores women’s voices. They remarked that capacity building needs to be a two-way process so that governments, businesses, and organizations can learn how to shape meaningful involvement.

“People think asking HIV-positive women to come and speak is enough; they need to be educated.” ~Workshop participant

Swazi workshop participants noted that they rarely if ever have the opportunity to develop prevention much less treatment materials; to monitor and evaluate HIV/AIDS-related activities; to engage in research; to implement government programs; and to attend conferences and conventions.

A.4 Other Access-to-Treatment Issues

Workshop participants reported that fluctuating and limited stocks of ARVs, overburdened healthcare services, and a lack of links to comprehensive care and support programs all pose barriers to treatment. While some of the barriers are not particular to women, they nonetheless affect women, sometimes disproportionately due to women's limited decisionmaking power and lack of time, money, and mobility (as detailed in Section A.1 above).

Stockouts of ARVs. Workshop participants reported that healthcare services do not always maintain stocks of needed drugs. At some large hospitals, women faced delays in initiating ARV treatment because of long waiting lists or stockouts. For women in particular, treatment delays are a hardship, occasioning additional travel costs and expenditures of time.

“Some people get ARVs free, but when they are out of stock there's no information until you arrive at the clinic to collect them with money you borrowed from your neighbor to get there on the right day, and then they tell you the meds are out of stock.” ~Workshop participant

Fees for ARV-related services. Although ARVs are provided at no cost in Swaziland, workshop participants reported that other medicines and tests are not free and therefore represent a barrier to treatment and care.

“[At the hospital] you pay for each test or analysis that you have done while you're there, so it can end up being very expensive.” ~Workshop participant

Overburdened healthcare services. Many healthcare clinics and hospitals face difficulties in meeting patients' service needs. Workshop participants reported that healthcare delivery points are characterized by overcrowding, shortage of staff, and long waiting lists and lines. With such conditions, women with time constraints may be unable to access care. Moreover, overburdened providers are less likely to take the time needed to explain to women in sufficient detail what they need to know about their condition and treatment.

Lack of comprehensive care, treatment, and support. Workshop participants listed additional needs related to nutrition and palliative care as part of comprehensive care and support. Obviously, nutrition is important for maintaining good health and can help delay the need for ARVs among people living with HIV/AIDS. Those already on ARVs require proper nutrition, as the medication must be taken with food. Moreover, practical solutions to nutrition and the production of healthy foods are essential components of care in view of women's role in food production and the tendency among women to place other family members' nutritional needs before their own when resources are scarce. Participants named palliative care as particularly important when women lack the resources to manage pain, especially given that women are customarily caretakers for others.

B. Policy Assessment Related to ACTS

The rapid assessment sought to evaluate Swaziland's current policy framework for relevant national instruments and guidelines related to HIV-positive women's ACTS. The assessment identified existing support, barriers, and gaps for HIV-positive women's ACTS and examined frameworks specific to access to ARVs as well as frameworks that address the broader range of issues and underlying gender barriers faced by women in accessing care, treatment, and support. In addition, the rapid assessment set out to identify strategic policy change opportunities, but the rapid assessment's short time frame hampered efforts as to establish ongoing conversations with allies familiar with the policymaking context. The discussion below therefore focuses on current policy frameworks.

ARV guidelines and plans. Swaziland's guidelines on the use of ARVs are based on the recommendations of the World Health Organization (WHO). In addition, Swaziland has promulgated guidelines on post-exposure prophylaxis and PMTCT. The guidelines address medical differences primarily in relation to pregnant women but do not address social and economic barriers that prevent equitable access to ART. In terms of violence against women, Swaziland has enacted no policies or legislation concerning the administration of ARVs to rape victims.

Swaziland's Ministry of Health and Social Welfare has developed an Emergency Care and Treatment Implementation Plan to initiate a phased scaling-up of ART. The government has already started to implement the plan. Seven treatment centers provide ARVs at no charge to people living with HIV/AIDS. The plan specifies strategies for strengthening human resource capacity for scaling up ART; ensuring adequate supplies of safe, approved, and affordable ARVs; promoting the availability of ARVs to children and to employees in the workplace; establishing a community-based ART support system; and ensuring a policy environment conducive to scaling up ART services at the community level. A community-based treatment program provides a potential opening for addressing gender-related constraints to ACTS, specifically in the case of social barriers faced by women.

Broader policy frameworks. The project found that a complete assessment of the policy environment for ACTS is a challenge. An enormous number of laws, policies, and guidelines affects women's ACTS across several sectors and levels. Nonetheless, the assessment examined a range of policies, including health sector policies and guidelines related to HIV, RH, PMTCT, VCT; women's rights-focused documents such as the draft Swazi gender plan and the new Constitution; and other sector documents such as the Swaziland National Development Strategy and found that none of the policies/documents articulates broad principles that address women's barriers to ACTS. However, specific gender barriers, when named, are more frequently articulated in relation to HIV-negative women than HIV-positive women. In addition, when documents do support the rights of people living with HIV/AIDS, they either articulate poorly or fail to address the barriers faced by women living with HIV. The assessment also highlighted the importance of

customary laws as well as traditions and social institutions such as the family/household and religious practices as areas that need to be addressed in supporting women's ACTS.

C. Participant Priorities and Action Plans

At the validation workshop held in June 2005 and in the subsequent advocacy capacity-building workshop in August 2005, workshop participants set priorities for their advocacy issues and developed advocacy action plans. The priorities and plans reflect the holistic understanding that women articulated in relation to ACTS. In particular, HIV-positive women identified actions related to equitable access to antiretroviral treatment as well as actions related to other types of care, treatment, and support and associated barriers.

Identifying advocacy priority issues. At the initial validation workshop, access to treatment emerged as a priority issue. In particular, ICW participants noted that the following three aspects of access to treatment are essential to ensuring ACTS:

Access to treatment

- **Decentralized treatment and supplies**
"We need treatment available in local centers, in home communities, and linked to local support groups." ~Group of workshop participants
- **Treatment literacy**
"We need to ensure every woman can get information and understand more about treatment. Many women do not know where to get treatment and need empowerment to know where to go. We need information in our mother tongue. We need campaigns, and to be sure enough time is allotted to campaigns." ~Group of workshop participants
- **Training for providers to achieve sensitive and holistic healthcare**
"Healthcare workers do not want to share information [with women] and are not given proper training on treatment [for women]." ~Group of workshop participants

Participants identified still other advocacy issues associated with women's access to care, treatment, and support and underlying barriers:

- Lack of information tailored to HIV-positive women on reproductive health;
- Stigma and discrimination that prevent women from using information and services effectively as a consequence of the lack of family and community support, fear of disclosure, and the threat of physical and mental abuse;
- Pressures and consequences related to disclosure;
- Lack of women's decisionmaking power in relationships with men owing to cultural norms and lack of economic independence; and
- Lack of solidarity among women.

Developing advocacy objectives and action plans. In the five-day advocacy capacity-building workshop in August 2005, participants narrowed their priorities and selected advocacy goals and objectives to achieve access to high-quality care, treatment, and support. The Swazi participants then developed three advocacy plans. The plans reflect ICW members' analysis that calls for addressing the root causes of barriers to treatment, in addition to achieving more immediate improvements in access to high-quality, holistic services. The goals and plans are as follows:

Goal 1—Access to high-quality services for HIV-positive women

Objective

- By 2010, ensure that the Ministry of Health makes available annual Pap smears for HIV-positive women as well as breast cancer services and free CD4 count and viral load services in all regional hospitals.

Strategies

- By December 2006, raise community awareness among women about the services the Ministry of Health is to provide.
- By December 2005, inform ourselves about currently available services and related gaps.

Goal 2—Care and support for HIV-positive women in their communities

Objective

- By December 2006, build the capacity of 200 HIV-positive women (50 women per region) to educate other HIV-positive women in their communities about the health services available at health centers/government hospitals.

Strategies

- By June 2006, lobby ICW to support capacity building and research for 200 HIV-positive women on health services available in health centers.
- By June 2006, conduct research on what services are available in health centers/hospitals.
- By December 2006, train and educate 200 HIV-positive women on available health services in hospitals (e.g., Pap smears, treatment of STIs, and so forth).

Goal 3—Uphold the property rights of HIV-positive women in rural and urban areas

Objective

- By December 2006, demand the development of a policy that protects and enforces the property rights of all HIV-positive women.

Strategies

- By June 2006, build coalitions with groups such as the Swaziland Federation of Trade Unions, Swaziland Federation of Labor, Federation of Swaziland Employers, Swaziland National Association of Teachers, Swaziland National Association of Civil Service, Swaziland Nurses Association, Coordination Assembly of NGOs, and faith-based organizations to support the development

of a policy that protects and enforces the property rights of HIV-positive women.

Putting advocacy into action. After some delays, ICW members in Swaziland began implementing their three advocacy action plans as of December 2005. ICW members' initial steps focused on refining members' understanding of locally (un)available services as a prerequisite to (1) educating other women about and increasing their use of currently available community-based services and (2) encouraging women's advocacy to address service gaps. ICW members have also initiated meetings with potential allies to increase awareness of HIV-positive women's barriers and needed changes.

III. Achievements

This activity clearly achieved its intended objectives. It built the capacity of HIV-positive women to assume leadership and advocacy roles in promoting ACTS. It also provided replicable tools and processes for use in other country contexts. Highlights of the project's achievements include the following:

- The project's rapid assessment and workshop process:
 - Identified barriers faced by Swazi women in accessing ARV and broader care, treatment, and support to maintain their health;
 - Highlighted current gaps in policy and program frameworks and identified possible solutions to support increased uptake of services; and
 - Prioritized issues for leadership and action by HIV-positive women at the community and national levels in order to increase women's ACTS.
- Capacity building led to increased skills for 20 HIV-positive Swazi women, enabling them to develop an increased understanding of barriers to ACTS and to formulate targeted advocacy plans to increase their ACTS at the community, facility, and national levels.
- ICW members are now implementing activities to increase the uptake of services by HIV-positive women in their communities and to improve the quality of available services. As part of these activities, the 20 women trained in the initial workshop are working to expand the cadre of HIV-positive women capable of educating 200 peers across Swaziland's four regions within the year on available and needed services.
- This activity designed adaptable tools and resources, including a rapid assessment process that can be used to assess women's barriers to ACTS; an advocacy curriculum aimed at and for use by HIV-positive women, with specific content related to ACTS; and documentation of lessons learned to strengthen ACTS advocacy efforts led by HIV-positive women.
- The project strengthened ICW as a global network by helping build other advocacy networks and coordinating action plans among members in Swaziland.

An important byproduct is a strengthened advocacy link between ICW's global network and its country and community-level networks. As ICW reflected in its final project report, the project:

"Has greatly enhanced the capacity of the two offices [one in Swaziland, and the other in South Africa] where these [ICW] staff members are based, to mobilize women living with HIV in these countries, to increase communications with ICW members, and within the staff structure of the network, and to support project work."

- With funds leveraged from other POLICY activities, two ICW members were able to participate in the USAID FP-HIV Integration Working Group meeting titled "Integrating Family Planning and ARV Programs" held in Washington, D.C., in November 2005. Current plans call for securing funds to support the continuing participation of ICW country members in the working group.

IV. Lessons Learned and Implications for Future Programming

The following lessons learned will help refine and expand approaches for future initiatives:

Supporting HIV-positive women in identifying barriers to ACTS and developing and implementing solutions contributes to increased uptake of services at the community level. HIV-positive women reached through the project were able not only to identify barriers to women's ACTS but also to develop practical solutions to overcoming these barriers in their communities. In addition, the project's approach to supporting women-led research and capacity building has increased the confidence and ability of HIV-positive women, enabling them to begin engaging with local and national level decisionmakers to influence the development of program and policy changes to support increased access to services.

Women's barriers to ARVs and the complexity of women's ACTS still remain largely unrecognized. When asked highly focused questions and given the opportunity to participate in fora to exchange ideas and experiences, HIV-positive women readily identified common barriers to access to treatment. In fact, the women often noted that, until they responded to the questions and participated in the fora, they had not considered barriers to ACTS and lacked information about basic issues related to treatment, much less treatment for women. Furthermore, the rapid assessment revealed that policies and program implementers do not account for women's barriers to treatment or treatment and care issues as related to women. Efforts to increase awareness of women's barriers to ARVs and ACTS at all levels—among donors, policymakers, program implementers, community leaders, men and women living with HIV—are a prerequisite to treatment programs that effectively and equitably meet women's goals.

Women-led and -designed treatment literacy programs are a critical, strategic point of intervention. HIV-positive women are uniquely positioned to become effective leaders in treatment uptake and adherence in terms of both educating other women in the

community and shaping policies and programs that address current barriers to treatment. In fact, most workshop participants felt sufficiently prepared to share information on women's rights with other women. Nonetheless, they still need sustained access to information and training materials to build their own knowledge and capacity and to educate and mobilize other women in their communities about how to access appropriate care, treatment, and support. Currently, such community-led treatment literacy programs do not exist in Swaziland, much less treatment literacy programs targeted to women. For women-focused treatment literacy programs to succeed, HIV-positive women need to shape the content and format of the materials and training programs. Current efforts to expand treatment literacy among networks of people living with HIV/AIDS must include women-focused treatment literacy, in addition to supporting HIV-positive women's groups, such as ICW, in developing needed materials.

Identifying policy-level advocacy opportunities to address women's access to treatment is challenging and requires considerable time. The original rapid assessment called for both an assessment of women's experiences in order to identify advocacy priorities and a mapping of the policy environment in order to identify advocacy opportunities. However, the identification of strategic policy openings is a time-intensive process that requires engagement with actors and arenas largely new and unfamiliar to ICW members. Therefore, in the future, ICW needs to allocate more time and resources to mapping the policy environment. One option would be to identify the advocacy issues first and then undertake the policy mapping, thereby permitting HIV-positive women to build needed advocacy skills and link their experiences and issues to an analysis of current policies, policy actors, and advocacy opportunities. A second option would be to solidify relations with allies familiar with policymaking arenas at the local and national levels in order to identify advocacy openings.

Customary law and its influence in familial and community relations needs as much attention as other policies and laws in addressing women's access to treatment. Customary law tends to govern the private areas of family and household decisionmaking as related to finances, inheritance, land and property ownership, and tradition. As a result, men still wield considerable control over female health decisions despite constitutional changes (Swaziland's new Constitution will be implemented in February 2006) that nominally give women equal status with men. Customary law has an enormous impact on women's ability to maintain their own health and access to healthcare. It is therefore essential to recognize the links between ACTS and various aspects of family or community life and to undertake multipronged advocacy efforts that address various the impacts of customary law.

It is important to increase opportunities for smaller, more frequent, and ongoing meetings, technical assistance, and mentoring. Ongoing support helps build skills, coordinate plans, and expand the support base for HIV-positive women. In particular, the project noted that:

- Convening large workshops with the same group of women allowed for crucial continuity in terms of building skills and strengthening networks. In fact, the two

sets of mini-workshops held with ICW members (one to build skills for participatory assessments and the other for public speaking and becoming trainers) were also cost-effective and productive. They provided an efficient and effective way to share information and explore issues, suggesting the need for expanded opportunities and resources dedicated to supporting regular, smaller meetings in order to convene ICW members already engaged in advocacy activities and to initiate activities with other women. In addition, women who are just starting to engage in advocacy need ongoing mentoring. The training workshop brought together women with different levels of experience and knowledge, some of whom were able to support and lead others. The strategy of pairing more and less experienced women in training workshops requires further exploration.

- Ongoing support to strengthen communication and networking among ICW members at the country level is crucial to consolidating input into decisionmaking fora and ensuring communication back to members. Communication and outreach are especially important to ensure that the most marginalized groups in society, such as women in rural areas of Swaziland, are actively included in networks and advocacy efforts so that the work carried out by a few is recognized by and benefits others. Those “few” must be truly representative of women living with HIV and have a voice in identifying issues that affect larger numbers of women.

“We cannot be expected to coordinate feedback from all our members. We need funding so we can consult with members and then take the information that we learn (in policy forums) back to them.” –Workshop participant

- Consistent mentoring of new and existing staff at the local level is important to help strengthen organizational development and advocacy skills. Participants viewed mentoring as effective in building leadership skills and agreed that mentoring should be an ongoing activity. In addition, the project provided an important opportunity to link global and local advocacy efforts, strengthening both in the process. Nonetheless, maintaining global-local linkages is a challenge in view of limited staff and financial resources at both the global and national levels, making it essential to dedicate resources to fostering such linkages.

Finally, the activity reaffirmed a central lesson reflected in other POLICY work—success requires sustained time and resources. The activity showed that, with sufficient support and skills, HIV-positive women can assume an active role in leading the response to HIV. At the same time, building leadership skills is time-intensive and requires an ongoing commitment. Local ICW members previously uninvolved in the response to HIV are beginning to assume leadership roles in the policy arena at the global, national, and local levels, but additional time and ongoing support are needed to help them fully realize the higher-level results stemming from their expanded leadership roles.