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TARGET OF OPPORTUNITY FINAL REPORT:

Meeting the Reproductive Health Needs of HIV-Positive Women: Using Evidence to Advocate for Change

POLICY Project

February 2006

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Meeting the RH Needs of HIV-Positive Women: Using Evidence to Advocate for Change

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Abstract

This target of opportunity (TOO) was a follow-up activity to the Swaziland *Sikanyekanye* core package. *Sikanyekanye* engaged both HIV-positive women and leadership from traditional and community structures to assess barriers and gaps to HIV-positive women's access to reproductive healthcare information and services and to initiate policy dialogue and advocacy activities. While *Sikanyekanye* actively involved HIV-positive women, it found that to promote their needs fully and effectively, advocacy activities should be *led* by HIV-positive women. Thus, the TOO was designed and implemented in partnership with the International Community of Women Living with HIV/AIDS (ICW) in South Africa and Swaziland to build HIV-positive women's capacity to raise awareness of their reproductive health needs by creating and implementing advocacy plans to reduce policy and operational barriers at facility, community, and national levels. Another TOO objective was to synthesize and facilitate the sharing of tools and the lessons learned across countries striving to meet the reproductive health (RH) needs of HIV-positive women.

To achieve these objectives, the project formed a multisectoral reference group to guide rapid assessments and desk reviews of HIV-positive women's RH needs in both countries, conducted a workshop for ICW members to validate the assessments' findings, created an advocacy training curriculum for ICW to use in a follow-up workshop, and helped to prepare and implement seven advocacy action plans at the community level. Some of the significant results included the following:

- Increased advocacy skills for 45 HIV-positive women, enabling them to promote their reproductive health needs at the community, facility, and national levels.
- Greater involvement of HIV-positive women in policy dialogue and formulation. For the first time, HIV-positive women in Swaziland are actively involved at the national level in providing input to the upcoming revision of the *National Sexual and Reproductive Health Strategy and Plan of Action 2002–2006*.
- A strengthened global network achieved through coordinated action plans among ICW's members in South Africa and Swaziland.
- New adaptable tools and resources, including a RH advocacy curriculum created by and for HIV-positive women and a synthesis report examining global research and POLICY's experiences in helping to promote HIV-positive women's RH needs.



Abbreviations

AIDS	acquired immune deficiency syndrome
ANC	antenatal care
ART	antiretroviral therapy
ARV	antiretroviral
FP	family planning
HIV	human immunodeficiency virus
ICW	International Community of Women Living with HIV/AIDS
IR	intermediate result
PMTCT	prevention of mother-to-child transmission
RH	reproductive health
STI	sexually transmitted infection
TOO	target of opportunity
UNFPA	United Nations Population Fund
USAID	U.S. Agency for International Development
VCT	voluntary counseling and testing



Introduction

From July 2004–December 2005,¹ POLICY, in partnership with the International Community of Women Living with HIV/AIDS (ICW), implemented the core-funded target of opportunity (TOO), *Meeting the Reproductive Health Needs of HIV-Positive Women: Using Evidence to Advocate for Change*, in Swaziland and South Africa. This report presents a summary of the key findings from the project’s rapid assessments on HIV-positive women’s reproductive health (RH) needs and details the project’s lessons learned and implications for implementing possible future activities.

¹ Initial discussions and planning with ICW for an HIV-positive women-led project were extensive, and therefore, project activities were not launched until January 2005.



II. Background

This TOO was a follow-up activity to the Swaziland *Sikanyekanye* core package. *Sikanyekanye* engaged both HIV-positive women and leadership from traditional and community structures to assess barriers and gaps to HIV-positive women's access to reproductive healthcare information and services and to initiate policy dialogue and advocacy activities around these issues. While the *Sikanyekanye* project actively involved HIV-positive women, it found that fully promoting HIV-positive women's roles in shaping policy requires that programs be led by HIV-positive women. As a result, the TOO was designed and implemented in partnership with ICW in South Africa and Swaziland. The TOO sought to build HIV-positive women's advocacy capacity to promote their reproductive healthcare needs by creating and implementing advocacy plans to reduce policy and operational barriers at facility, community, and national levels. The project also made strengthening the local and national networks of ICW in South Africa and Swaziland a priority.

Project activities and objectives

The TOO's specific objectives were to

- strengthen the capacity of HIV-positive women's networks to advocate for improved policies and guidelines to better address the family planning (FP) and RH needs of positive women in Swaziland and South Africa,
- support countries to develop relevant policies and guidelines to better address RH needs of HIV-positive women, and
- produce materials to synthesize and facilitate the sharing of key tools and lessons learned.

The project's main activities included the following:

- forming a multisectoral reference group to provide strategic guidance and to increase support for undertaking rapid assessments in South Africa and Swaziland and for building the capacity of HIV-positive women in those countries.
- undertaking a rapid assessment to examine HIV-positive women's RH needs; current policy barriers; and opportunities for change at community, facility, and national levels in both countries. (The assessment process included a combination of desk reviews and interviews with HIV-positive women, including 25 ICW members in South Africa who also conducted interviews.)
- conducting a validation workshop with 43 ICW members from both countries to validate the findings of the rapid assessment and identify priority issues for advocacy.

- designing an advocacy training curriculum on HIV-positive women’s reproductive health—created by and for HIV-positive women that would also be available for subsequent advocacy and policy development efforts in other countries and regions.
- conducting an advocacy training workshop with 45 ICW members from both countries to strengthen advocacy skills and prepare advocacy action plans for important RH issues. (The seven action plans—five in South Africa and two in Swaziland—address alternative means of conception, care and support, property rights, adoption policy, ethical research, and high-quality services.)
- assisting HIV-positive women with implementing the seven action plans at the community level, which involved advocating for improved services and increased participation in the policy process and helped synthesize their input for national policy dialogue. (Activities included a second workshop with 15 women in Swaziland aimed at strengthening public speaking skills, the ability to support other women in their communities, and confidence levels.)
- throughout the project process, working to strengthen the organizational capacity of ICW’s networks in South Africa and Swaziland.
- as an adjunct activity using IR1 funding, reviewing POLICY’s experiences and drafting a synthesis report that outlines the RH needs of HIV-positive women, barriers to improving their RH status, and promising strategies for advocacy and policy change to overcome these barriers and meet their needs.



Summary of Rapid Assessment Findings

The rapid assessments were undertaken to gain a clearer understanding of the policy environment, the specific issues affecting HIV-positive women, and the advocacy opportunities for policy and programmatic change. The following is a summary of the main findings from the project's rapid assessments, including desk reviews and a validation workshop (see Appendix 1 for a complete list of findings).

Voluntary counseling and testing (VCT)

- *HIV testing.* HIV-positive women from South Africa and Swaziland reported that HIV testing is often not voluntary.
- *Testing sites.* The focus on HIV testing at antenatal care (ANC) sites discourages male involvement and responsibility and limits the ability of women to learn of their status at a time when they could better cope with the test results.

Disclosure and partner notification

- *Fear of disclosure.* Women reported that their decisions regarding disclosure of their HIV status were influenced by a fear of violence or the loss of resources (homes and livelihoods) and relationships.
- *Lack of testing for men.* Since testing usually occurs during pregnancy-related or RH care, women feel there is less responsibility on men to get tested and disclose their HIV status to their partners. Almost all the participants believe that men live in denial concerning their sexual health, and feel the responsibility was generally on women to initiate such discussions.
- *Role of breastfeeding.* The stigma associated with not breastfeeding can lead to the disclosure of a women's HIV status.

Information and decisionmaking

- *Limited knowledge of RH options.* HIV-positive women's access to RH information and counseling to help them make decisions about their reproductive healthcare is limited. Rural women and non-English speakers have particular difficulty in accessing information to support their decisionmaking.
- *Pressure to have children.* HIV-positive women experience pressure to have children due to the cultural norm that a woman's role is to bear children. However, HIV-positive women also face discrimination when they choose to have children—from healthcare providers, family members, and communities.
- *Lack of awareness of prevention of mother-to-child transmission (PMTCT) services.* Many women are unaware of PMTCT programs and PMTCT information often focuses only on the child.
- *Sterilization pressure.* Women's ability to make their own decisions regarding sterilization is limited, as women often need the consent of partners. Many women also reported pressure to be sterilized; some women reported being asked to consent to sterilization or to use other forms of birth control methods in order to access antiretroviral therapy (ART) services.

- *Termination of pregnancy.* In South Africa, HIV-positive women experience discrimination related to fertility, such as pressure to abort when pregnant.

Healthcare services

- *Limited access to and availability of RH and integrated care.* FP, ANC, sexually transmitted infection (STI) treatment, and VCT services are offered in many clinics and hospitals, but mostly in urban areas. Women desire access to integrated services.
- *Lack of tailored services.* Women feel that there are no services tailored to the RH needs and concerns of HIV-positive women. In addition to the lack of specific information for HIV-positive women, many women do not know what pap smears are and do not have access to these services.

Healthcare providers

- *Low quality of care.* HIV-positive women often encounter stigma and discrimination—especially related to their reproductive health and sexual relations—from healthcare providers with judgmental and negative attitudes. Many women who said they did not feel comfortable using services cited bad treatment from healthcare workers.
- *Lack of resources and staff.* Even when positive women are able to seek care from healthcare providers, the quality of treatment is affected by a lack of resources. Because of high staff turnover, there is a shortage of health personnel in many service sites.

Structural barriers to improving HIV-positive women’s reproductive health

- *Lack of funds and distance to services.* Some positive women’s ability to access care is limited by their lack of resources. This is particularly true for women from rural areas, as they must travel to visit clinics.
- *Cultural norms/women’s status.* Cultural norms and women’s status affect women’s ability to access services. For instance, many women need to obtain consent from partners or in-laws to seek services, and may be inherited by their spouse’s male relative after the death of their husband. Women from rural areas are more likely to report these kinds of pressures.
- *Lack of power in sexual relationships.* Women express different degrees of power in sexual relationships, with most feeling that male partners dominate the actual act of sex. Generally, women encounter difficulties in ensuring that their partners remain monogamous, using barrier methods, and seeking HIV testing or STI treatment.
- *Limited access for young women.* Young women have limited access to healthcare services, along with limited knowledge of reproductive health matters. They are often denied services if their parents are not there to give consent.
- *Gender-based violence.* Many women experience and fear violence in their relationships. These women feel unable to refuse unwanted sex and/or practice safe sex. In addition, some women do not seek treatment for reproductive health problems for fear of violence or abandonment from their partners.
- *Lack of involvement of HIV-positive women.* Positive women feel that their issues are generally sidelined or ignored, saying that they are not involved in decisionmaking or the implementation of government programs.

Avenues for HIV-positive women's improved reproductive health

- *Positive women's support groups.* Women reported that support groups facilitate discussion of issues specific to HIV-positive women and help women to assert themselves. Women feel that those who are not in support groups are less likely to know where to get treatment and who to talk to, and they find themselves isolated without someone to share their experiences with.
- *Community and family support.* Positive women's partners express willingness to help and provide support but cite a lack of knowledge on the needs of HIV-positive women and on HIV/AIDS in general. Community support groups need increased and improved capacity for project management and formulation and financial management.

IV. Project Achievements

The TOO achieved its intended objectives; it increased the capacity of HIV-positive women to lead advocacy efforts to promote their RH needs and provided replicable tools and processes for use in other country contexts. Highlights of the TOO's achievements follow.

- Capacity building led to increased skills for 45 HIV-positive women, enabling them to understand and undertake advocacy activities to promote their RH needs at the community, facility, and national levels.

“I look forward and I am also excited, though I know this is not going to be easy, but I know it is possible. I know that with proper funding and capacity we can make a difference in women’s lives.”

~ Participant

- The TOO led to greater involvement of HIV-positive women in policy dialogue and formulation. ICW members formulated advocacy plans to improve services in their communities and are starting to engage local decisionmakers to respond more adequately to their needs. Also, for the first time, HIV-positive women in Swaziland are actively involved at the national level in providing input to the upcoming revision and adaptation of the *National Sexual and Reproductive Health Policy*. Participants were optimistic about these plans.

“Most times we plan but the plans fail. This time I feel that we are going to succeed.”

~ Participant

- The TOO strengthened ICW as a global network by supporting the formation of advocacy networks and coordinated action plans among its members in South Africa and Swaziland. An important byproduct has been linking its global network to emerging networks within the two countries.

“[POLICY support] has greatly enhanced the capacity of the two offices [in Swaziland and 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.”

~ Participant

- The TOO designed adaptable tools and resources, including a RH advocacy curriculum created by and for HIV-positive women, which is an important tool to engage vulnerable groups; documentation of lessons learned to strengthen RH advocacy efforts led by HIV-positive women; and a synthesis report examining global research and POLICY's experiences on the current status of meeting HIV-positive women's RH needs. (See Appendix 2, List of Products).

- With funds leveraged from other POLICY activities, two ICW members participated in the USAID FP/HIV working group meeting “Integrating Family Planning and ARV Programs,” held in Washington, DC, in November 2005, and four ICW members participated in the EngenderHealth/UNFPA pilot training for healthcare service providers to better promote positive women’s reproductive health, held in Addis Ababa, Ethiopia, in December 2005. ICW was also promised funding from the Open Society Initiative for Southern Africa to continue its advocacy efforts.



V. Lessons Learned

The following lessons learned will help to refine and expand approaches for use in related future initiatives:

Building capacity to map the policy environment and advocacy opportunities is challenging and requires dedicated time to accomplish. The original rapid assessment was designed to include both an assessment of women’s experiences to identify advocacy priorities and a mapping of the policy environment to identify advocacy opportunities. However, while of tremendous interest, assessing the policy environment required engagement with actors and arenas largely new and unfamiliar to ICW members, which took considerable time. In the future, we need to allocate more time and dedicated resources to mapping the policy environment. One option would be to identify the advocacy issues first and then undertake the policy mapping. This would allow ICW members to build desired advocacy skills and to more closely link their experiences and issues to an analysis of current policies, policy actors, and advocacy opportunities.

It is important to increase opportunities for smaller, more frequent meetings, technical assistance, and mentoring. Such ongoing support helps to build skills, coordinate plans, and expand the support base for ICW members.

- Participants and project planners thought that convening large workshops with the same group of women allowed for crucial continuity in terms of skills building and network strengthening. However, the two sets of mini-workshops held with ICW members (one to build skills to carry out participatory assessments and the other to build public speaking and training-of-trainer capacity) were also cost-effective, productive, and a fast way to share information and explore issues. Opportunities to support regular, smaller meetings to convene ICW members already engaged in advocacy activities and to initiate activities with other women should be expanded in the future. Also, providing ongoing and responsive technical assistance to support advocacy plans throughout implementation and to create specific advocacy materials is crucial.
- POLICY provided ongoing mentoring to new and existing ICW staff to help strengthen organizational development and advocacy skills. This mentoring was viewed as effective in building leadership and should be continued in the future. To further increase effectiveness, both parties should clearly define the mutual expectations of mentoring.

There is a need to strengthen the capacity of community-led networks to help build support for advocacy efforts, such as women-led awareness raising and education sessions and materials for other community women. Helping to build ICW members’ skills in community education and awareness raising would enable greater community participation in the advocacy and monitoring of policy changes related to HIV-positive women’s reproductive healthcare.

The project also reaffirmed that communities need technical assistance focused on creating and implementing policies and guidelines at the local level, especially to improve clinics' and local faith-based organizations' ability to address HIV-positive women's reproductive healthcare needs.

Finally, this activity reaffirmed a key lesson in other POLICY work—success requires sustained time and resources. The activity showed that with sufficient support and skills, vulnerable groups can take an active role in leading the response to HIV. At the same time, building the leadership skills of marginalized and vulnerable groups is time intensive and requires a dedicated level of effort. ICW members are beginning to assume leadership roles in policy responses at global, national, and local levels; however, their ability to do so was largely due to POLICY's considerable investment of time and technical assistance to build these skills. Additional time is needed to fully realize higher level results stemming from their increased leadership roles.



VI. Implications for Future Programming

Replication of Process

This TOO was successful in working with HIV-positive women to build network capacity to initiate and undertake advocacy and policy change around RH issues. As such, the POLICY Project and our collaborator, ICW, plan on including numerous central components of this project in future efforts.

ICW's use of approach and tools. Pending additional funding, when replicating the project in other countries, ICW will use tools developed specifically for the TOO, such as the RH advocacy curriculum, and the project's overall participatory approach to increase positive women's involvement in advocating for their reproductive health. ICW plans to replicate the processes of forming a leadership team of positive women, conducting a rapid assessment of women's experiences and the policy environment, and then using the curriculum to build advocacy skills to prepare country-specific action plans.

POLICY's application of a participatory approach. POLICY is now well situated to replicate its work with other vulnerable groups. In particular, we recommend that future projects include the following elements:

- Partnering with vulnerable groups to support their leadership, with POLICY's technical assistance, including
 - capacity building in technical approaches (e.g., policy assessment, advocacy training, formation of advocacy strategies, etc.); and
 - supporting organizational development and network strengthening.
- Promoting leadership by vulnerable groups in all phases of the project, especially in developing and implementing technical approaches, including the
 - rapid assessment of vulnerable groups' experiences;
 - mapping of the policy environment;
 - creation of training curriculum materials; and
 - preparation of advocacy action plans.
- Forming an activity reference group to broaden networks and create collaboration among allied organizations, including those who have familiarity and influence within formal decisionmaking processes with which vulnerable groups may have less experience.
- Sustaining the involvement of the same group of participants as they deepen their skills and relationships and implement their action plans, while building the capacity of a core group of participants to engage other peers in the process.
- Dedicating specific funds for community groups to implement action plans and for related consultation, coordination, and follow-up among involved groups.

Moving Forward

Future projects should examine and build on the TOO's work to further strengthen positive women's leadership and implement policy changes to address operational barriers, especially where they have a local impact.

Strengthening positive women's leadership. To adequately address positive women's RH needs, positive women must continue to participate as policy champions for their issues. When working to expand the next generation of HIV-positive women's leadership, the following elements are essential:

- Consistent mentoring for HIV-positive women leaders at the community and national levels to build their own skills for policy dialogue and advocacy, such as public speaking and participation in formal meetings, familiarity with the policymaking process, and improved skills in policy formulation and analysis.
- Support for HIV-positive women leaders to raise awareness and transfer their knowledge and skills to peers, including the *women-led* development of
 - awareness raising and education related to HIV-positive women's reproductive health, and
 - peer training in public speaking and other policy dialogue skills.
- Strengthen consultation and communication processes among vulnerable groups from the local to national level and vice versa to assure adequate representation and communication related to policy dialogue and formation (this includes ensuring dedicated funds and organizational strengthening).

Implementing policy changes to address operational policy barriers. To move forward, technical assistance should focus on creating and implementing operational policies and guidelines at the local level. In particular, future efforts should consider the following approaches:

- Sharpening policy assessment processes to identify mechanisms to affect operational barriers at the local level. While there are many barriers to implementing local policies, it is often not clear what specific processes exist and which would be most useful.
- Providing technical assistance in facilitating policy dialogue and change processes related to operational policy barriers at the local level, as engaging in these processes will likely involve skills and strategies new to local actors.
- Documenting the processes, impact, and lessons learned in bringing about policy change, including efforts to improve clinics' and local faith-based organizations' ability to address HIV-positive women's RH needs; promote mechanisms to involve women in decisionmaking and leadership; and strengthen the capacity of local leaders, healthcare providers, and HIV-positive women to understand and effectively educate others on positive women's reproductive health.



Appendix 1

Key Findings from the Rapid Assessments

The rapid assessments in South Africa and Swaziland were designed to gain a clearer understanding of the specific reproductive health issues affecting HIV-positive women. Following the assessments, participants discussed the findings in the validation workshop and offered valuable input. The findings were later used to help inform the advocacy training workshop and were incorporated into the final version of the rapid assessment report.

The rapid assessment and desk review in South Africa involved collecting data from 25 women who then participated in the validation and advocacy workshops. The 25 participants committed to carrying out additional interviews with other HIV-positive women. As a result, by the time of the validation workshop, participants were relatively familiar with the themes and had begun to analyze their own experiences. In Swaziland, the rapid assessment and desk review drew and built on various workshops and projects that had occurred in the country over the previous year. The process involved many women who had participated in these projects, lending continuity to and building on those activities. Thus, the report findings included the experiences of a larger number of women.

The following are key findings from the project's rapid assessments, desk reviews, and the validation workshop. The findings are primarily left in the participants' words to convey HIV-positive women's reality. Their concerns can be used to inform future work addressing HIV-positive women's RH needs. The findings from the initial rapid assessments are marked with the country they came from; findings followed by "validation" emerged from the validation workshop and are not identified by country as workshop participants were from both countries.

Voluntary counseling and testing

HIV testing. HIV-positive women from South Africa and Swaziland reported that HIV testing is often not voluntary.

- "I know an HIV-positive woman who was told to get tested but she knew nothing and then was told she was positive. They gave her the meds without details and she uses some meds for her kids because she does not understand. She was forced to take the test." (Validation)
- "It is not about choice. In [antenatal] clinics you have to do it whether you know your status or not. I know I am HIV positive but they say we have to do it. When I went to the clinic, I said I know my status but the nurse said I have to do it [the test] otherwise I won't give you treatment." (Validation)
- "Women are forced to test when they are not ready." (Validation)

Testing site. Women noted that the focus on HIV testing at ANC sites discourages male involvement and responsibility and limits the ability of women to learn of their status at a time when they could better cope with the test results.

- In South Africa, HIV testing primarily occurs while receiving ANC. ANC statistics are used for estimating HIV prevalence. Sentinel surveillance in ANC sites reinforces the mistaken notion that women bring HIV into the family since men are not being tested in these sites.
- Because pregnancy is an emotional period in women’s lives, testing women for HIV and learning of one’s positive status at this time can be traumatic.

Disclosure and partner notification

Women’s disclosure. Women reported that their decisions regarding the disclosure of their HIV status were influenced by the fear of violence or the loss of resources (homes and livelihoods) and relationships (including bargaining power within the relationship).

- “If we disclose upfront, these guys won’t want to be involved. If we disclose in the middle of a relationship, we might have to start another relationship.” (South Africa)
- “There is no support for women who lose livelihoods and dignity because of disclosure, so we worry about advocating for disclosure as activists. This woman has tried to access legal services but she can’t because she doesn’t have a job. Her partner can afford legal services, so he is getting everything while she gets nothing. He is also getting the support of his family and friends, despite being positive himself.” (South Africa)
- “When I disclose, I lose my power. If he stays with me, he is doing me a favor—maybe another man would not stay. He acts like he made a sacrifice.” (South Africa)

Men’s disclosure. Since testing usually occurs while receiving pregnancy-related or reproductive healthcare, women feel there is less responsibility put on men to get tested and disclose their HIV status to their partners. Almost all the participants believe that men live in denial concerning their sexual health. As a result, women do not expect men to be open with them about their status and feel the responsibility is generally on them to initiate such discussions.

- “Guys—they are all negative—that’s what they tell you.” (South Africa)
- “Men won’t offer that information.” (South Africa)
- “I want him to tell so I know, even if I won’t know if he is telling the truth or not. I have always seen disclosure as my responsibility. I have never expected him to disclose to me. They will tell you they haven’t been tested. My partner doesn’t care, doesn’t want to test. Yet it is the first thing I want to say to anyone who will be my friend.” (South Africa)
- “They may assume responsibility to protect us. Now they think they get condoms to protect them from women.” (South Africa)

Breastfeeding. Stigma associated with not breastfeeding can lead to the disclosure of a woman’s HIV status. In South Africa and Swaziland, breastfeeding is a cultural norm and using formula milk often leads others to believe that the mother is HIV positive.

- “It is assumed you are HIV positive [if you don’t breastfeed].” (South Africa)

- “If you are living alone, not breastfeeding makes sense, but if I am a married woman, have just found out [my positive status], and am not ready to tell my partner, then breastfeeding is probable.” (South Africa)
- “If you bottle feed, you have to explain and you are effectively disclosing your status.” (South Africa)
- “In my case, the thing that is stigmatized is going to fetch the milk each and every week. It is collected from a particular room and if you go to that room, they know you are HIV positive. At the clinic, room number 10 is for HIV-positive women strictly. If you get milk and nutritional powder, they know the child is HIV positive and that gets women stigma. However, the powder is not just for HIV babies but for those suffering from malnutrition, but they are treated as if they have HIV.” (South Africa)
- “Even though if I’m not there and my child is crying, my mother-in-law will give him a bottle of formula milk. However, just getting the formula milk is stigmatizing—people already know you are getting it because you are HIV positive.” (Validation)

Information and decisionmaking

Availability of RH information. HIV-positive women said that access to information on RH options is unreliable. When HIV-positive women use healthcare services, they are often not told of all the options available to them. Women believe that doctors do not encourage them to understand their own health problems and needs. Information is often not comprehensive enough for the needs of HIV-positive women. Few women feel informed about alternative methods of conception, such as in-vitro fertilization (IVF), for HIV-positive women who want to have children or discordant couples. Rural women and non-English speakers have particular difficulty in accessing information.

- “They don’t give you a chance to say I don’t want 2 and 3. They say you can only have 3 and 4 because you have HIV. They don’t give you a choice.” (South Africa)
- “You are given your file and you carry it around but you are not supposed to look in it.” (Swaziland)
- “If you want to have a child, it’s hard to know who to talk to.” (South Africa)
- “We need a practical tool for this kind of basic information to be distributed in local languages.” (Validation)

Fertility. HIV-positive women experience pressure to have children due to the cultural norm that a woman’s role is to have children.

- “If the in-laws paid lobola [dowry] then they decide how many children, because they bought you to sustain the clan.” (South Africa)
- “Even if you have many children, you should continue falling pregnant until you have a boy. If you don’t have children, you are less of a woman. You lose everything, even your inheritance.” (South Africa)

However, women also face discrimination when they choose to have children—from healthcare providers, family, and communities.

- “If I want to marry and fall pregnant—they say why, you are HIV positive, everything is questioned and criticized.” (South Africa)
- “...When I got HIV, I only heard you are going to die and cannot have children, and my mother told me it’s a sin to have a child. Because they know I have HIV, they [neighbors] start to create stories. My husband, who is stupid, he came to tell me that if you have a child it will have HIV, but we have gone through everything and now he is starting to doubt every decision. He started to believe what was on the street. He thinks I am going to die of HIV.” (South Africa)
- “How come she got pregnant when she is HIV positive? She should practice safer sex!” (Swaziland)

Information related to prevention of mother-to-child transmission. Limited numbers of women are aware of PMTCT programs. Adequate care before, during, and after pregnancy is lacking. In addition, PMTCT programs tend to focus on the health of the baby only. Advice is often limited to instructions about breastfeeding or giving formula milk.

- “They do not give you information on motherhood, you give birth and you go.” (South Africa)
- “If you choose to have PMTCT, it should not start when you are pregnant, but when you want to have a child. Then we can protect ourselves and partners from infection or re-infection. There is sperm washing. Where the woman is infertile or sterile she can have IVF. This is available only in private clinics and not in public hospitals.” (South Africa)

Sterilization. In Swaziland, women’s ability to make their own decisions regarding sterilization is limited, as women need the consent of partners or parents for some procedures (if not married); women in South Africa reported instances of needing a partner’s permission to be sterilized.

- “I have five children and am expected to have another because I do not have a son. I went to the hospital to be sterilized. They wanted the husbands’ consent, but he wouldn’t as he did not have a boy child.” (South Africa)

However, women more often reported pressures to be sterilized, especially in South Africa. Since many healthcare providers believe that HIV-positive women cannot safely have children or should not have children, they often encourage or force sterilization upon patients. In addition, there is some evidence that women are asked to consent to sterilization or the use of birth control methods in order to access ART services.

- “Nurses and doctors will push a woman. One woman wanted to put her baby up for adoption, but she had to agree to be sterilized. Two years later, she returns and wants her baby back. If she was told about PMTCT, she would not have taken the decision to lose the baby. She was pressured to sign the form before having a caesarean section.” (South Africa)
- “When I was on a stretcher, a nurse brought me a form and said you must sign this—it was a sterilization form. I refused.” (South Africa)

Healthcare services

Availability of RH and integrated care. FP, ANC, STI treatment, and VCT services are offered in many clinics and hospitals, but are lacking in rural areas. Certain services are not always offered at the women’s local or regular clinics, limiting women’s ability to seek care. Women requested that comprehensive services be available to them.

- “I tried to find out about reproductive issues for positive women, but it is not clear, no one wants to claim responsibility.” (South Africa)
- “When I enter a clinic, I want to enter a women’s health center where they know what to do.” (South Africa)
- “Women come in for an HIV test, but while she’s talking, you find out that she also suspects that she’s pregnant; she needs to be able to do a pregnancy test while she’s there—or we have to refer her to somewhere else to do the pregnancy test and she gets no follow-up for the HIV diagnosis...we need a one-stop shop.” (South Africa)

Tailored services. Women feel that there are no services tailored to the RH needs and concerns of HIV-positive women. For example, positive women are at greater risk for cervical cancer and should have a pap smear every year. A number of women do not know what pap smears were, and the majority do not have them or have them regularly enough.

- “If you go for a pap smear, they will ask you who told you. If you say for example the Treatment Action Campaign, they say well you can go back to them. Why do you come here? Do you feel pain? Most are like that.” (South Africa)
- “Some go because the doctors motivate them, but some don’t know and the doctor doesn’t encourage them. There is also an age restriction. Women under 30 years are told—what’s the point? Then it’s only every five years. We need pap smears more often. They do not take our issues into account.” (South Africa)
- “When you have a pap smear, you have to give a reason and you may be disqualified because of your age.” (South Africa)
- “I tried to get guidelines on one issue because a nurse did not want to do a pap smear on a positive woman.” (South Africa)

Healthcare providers

Quality of care. HIV-positive women often encounter stigma and discrimination from healthcare providers with judgmental and negative attitudes. Many women who said they did not feel comfortable using services cited bad treatment from healthcare workers. In the face of this type of treatment, positive women have difficulty expressing their health needs and concerns.

- “There is no confidentiality, privacy, or dignity when you go to government clinics. Wherever you are, you get treated like an alien from Mars. The attitudes of the staff make many not go back.” (South Africa)
- “When rural women get the service provider they [often] meet an arrogant nurse, [so] she leaves feeling like nothing and will not return. So, if you have problems again, she will not go to the hospital and will die. I know an older woman—she

has cancer but does not want to go to the hospital because of the attitudes of the health workers.” (South Africa)

- “The staff are very judgmental; they just assume that you are sleeping around.” (South Africa)
- “Counselors are not supportive, are judgmental, they do not give help, they are gossipers, and do not respect our confidentiality.” (Swaziland)
- “Health workers are not committed to our issues; they impose their ideas about treatment and testing and do not respect us.” (Swaziland)
- “If you come to the clinic and tell the health worker or nurse what you need, they will refuse to help you—they don’t like it when patients are well-informed about their own condition.” (Validation)

Lack of resources and staff. Even when positive women are able to seek care from healthcare providers, treatment is affected by a lack of resources. Often, medication and services are not available or are not made available to positive women. In addition, healthcare facilities experience high staff turnover, resulting in a shortage of health personnel in service delivery. Patients often face long queues and sometimes return home without being seen.

- “Sometimes the meds are supposed to be there—they are on essential drug lists. But they are not there—we don’t receive them.” (South Africa)
- “I wanted prophylaxis when I had herpes, and I was told that it was too expensive for the government.” (South Africa)
- “One doctor didn’t check on me and referred me to a gynecologist, and I couldn’t get an appointment for five months.” (South Africa)
- “In hospitals, if you don’t know anything, then you are lost because they are so short staffed.” (South Africa)
- “There are not enough staff and long waiting lists, periods, and queues for care and treatment.” (Validation)

Structural barriers to HIV-positive women’s reproductive health

Economic and geographic barriers. Some positive women’s ability to access care is limited by finances. This is particularly true for women from rural areas, as they must travel to visit clinics. The cost of travel is a significant issue. For example, a South African woman had to take four taxis to go to the clinic and pay 80 rand. In some cases, women are forced to disclose to their families to get money for travel.

- “In Swaziland, hospital costs vary—you pay for each test or analysis that you have done while you’re there, so it can end up being very expensive. Sometimes a visit will result in a referral to a specialist clinic; there are only 4 of these in the country.” (Swaziland)
- “A mobile clinic comes to the community once a month. There is no political commitment to these communities—there should be a clinic everyday.” (South Africa)

Cultural norms/women’s status. Cultural norms and women’s status affect women’s ability to access services. In Swaziland, many women need to obtain consent from partners or in-laws to seek services, and may be inherited by their spouse’s male relatives

after the death of their husband. In areas where lobola is paid for a marriage, society maintains that men are in charge. Women from rural areas are more likely to report these kinds of pressures. With women's dependence on men and lack of self-empowerment being significant issues, women call for a more supportive family environment.

- “A man will say ‘I paid lobola. Why do you want to use a condom?’ You are there to make children.” (South Africa)
- “I am married now and his youngest brothers have three or four wives and they don't use condoms; it is a taboo. When they have more than one wife, the man decides where he will sleep tonight; you have to play by his rules.” (South Africa)
- “Members of family tend to set ground rules for me, making me not want to tell my parents about my status.” (Swaziland)
- “If you go to the mother-in-law, they say he was taking his rights as a husband.” (South Africa)
- “Our culture is a problem sometimes because there is a belief that a man's word is final—so this gives Swazi women less or no opportunity to decide on sexual and reproductive issues. If a woman is married and lobola paid, even the family believes they have something to say. They believe that sex is for a man's pleasure.” (Swaziland)

Power in sexual relationships. Women express different degrees of power in sexual relationships, with most feeling that male partners dominate the actual act of sex. Generally, women encounter difficulties in partners remaining monogamous, using barrier methods, and seeking HIV testing or STI treatment.

- “He does not force me to have sex, but he does emotionally because if I don't, then I don't get money, he might leave or won't talk to me; this spoils the mood of the house—so I feel obliged.” (South Africa)
- “I had a horrible partner. When I was married, he forced himself on me. He had an STI and gave it to me. Then when I treated it, he asked me where I got it from. He refused to use a condom; he knew he had an infection and wanted to pass it on to me. So what does a young married woman do? There is silence in marriage. I learnt to find a voice.” (South Africa)
- “My boyfriend is from the north and they laugh at him because he only sees me. They need to express their manhood by having a string of women.” (South Africa)
- “When you know their status and want to use a condom, you have to initiate the conversation. Men will not suggest using a condom.” (South Africa)
- “They [men] hold the condom in their right hand while they are busy penetrating you.” (Swaziland)
- “If a woman says she wants to use a condom, the man says it is my decision; it is Swazi law that the man's voice is final.” (Swaziland)
- “Married women cannot say no to husbands. They also do not want to embarrass their parents by not being submissive.” (Swaziland)
- “If they say no, they are scared the husband will go. He is financially stable and I am not working. Men are the head of the house—that is it.” (South Africa)

Young women. Young women have limited access to healthcare services, along with limited knowledge of reproductive health matters. They are often denied services if their parents are not there to give consent.

- “When I got pregnant and had HIV at 16, I only knew my school and local community. I wasn’t allowed out as a young woman; only men were because it was dangerous. So I knew nothing. How could I know what to ask for at the clinic? We can’t assert our rights because we don’t know our rights.” (South Africa)

Gender-based violence. Many women experience and fear violence in their relationships. These women feel unable to refuse unwanted sex and/or practice safe sex. In addition, some women do not seek treatment for reproductive health problems for fear of violence or abandonment from their partners. Domestic violence is viewed as a private family matter and is often sanctioned by other family members, including mothers-in-law.

- “You get beaten and then you have to have sex afterwards and you cannot ask for safe sex and you have a pain in your head and you cannot negotiate safe sex.” (South Africa)
- “Women believe they can accept abuse from men because they benefit from them financially. He is buying clothes for you. You don’t have a place to stay. He decides whether to use a condom or not...” (Validation)
- “One lady said when her son beats his wife that he is not beating her properly. If he rapes her and the wife goes to the granny—she says that’s your job and you must have children.” (South Africa)
- “It is all over the country [Swaziland].” (Swaziland)
- “After being tested, we go home and share the results. The partner does not accept you. Then there is fighting at home. We expect husbands to give warmth. Even though we are positive, we still need care and support.” (Swaziland)
- “When I was diagnosed, I had a partner. The relationship became more violent—he said I brought a new problem into the family. The violence became more; he had other relationships. You get told off because you have HIV. He dates other women, but you don’t want to leave because you don’t want to be defeated. He says ‘You have AIDS anyhow so you can’t compete with me. I have to have a life. You have HIV and won’t be around. So understand my other relationships.’” (South Africa)

Greater involvement of HIV-positive women. Positive women feel that their issues are generally sidelined or ignored, saying that they are not involved in decisionmaking or the implementation of government programs. They believe they should be given opportunities to develop new skills and participate in the drafting of prevention materials, research, policymaking, and program implementation.

- “Men that are decisionmakers feel that women’s place is in the kitchen. We don’t feel part of the decisionmaking community.” (South Africa)
- “We have organizations, but men lead the organizations and our issues don’t get discussed.” (South Africa)
- “Policymakers sit in boardrooms and decide what is relevant to our lives—we are not part of the process.” (South Africa)

- “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.” (Swaziland)
- “We have programs at the community level, but we are not fully supported by the government and we should be involved 100 percent.” (Swaziland)

Avenues for HIV-positive women’s improved reproductive health

Positive women’s support groups. Positive women recognize the importance of support groups, calling for additional resources to sustain them. Support groups facilitate the discussion of issues specific to HIV-positive women and help women to assert themselves. Women feel that challenges for those not in support groups are much greater. They don’t have access to care or know where to get treatment and who to talk to, and they find themselves isolated without someone to share their experiences with. However, some women feel that support groups need better unity.

- “Since I go to support groups, I am able to choose.” (South Africa)
- “My support group has supported me and given me information and I am fine. They have sorted the problem with the doctor. When women knew their rights and knew about health problems, they felt they were able to secure what they needed from the service providers.” (South Africa)
- “There is a problem of stigma and discrimination amongst us as HIV-positive women.” (Validation)

Community and family support. Positive women’s partners express willingness to help and support their partners, but cite a lack of knowledge on the needs of HIV-positive women and on HIV/AIDS in general. Community support groups need increased and improved capacity for project management and formulation and financial management.



Appendix 2

List of Products

- “Meeting the Reproductive Health Needs of HIV-Positive Women: Using Evidence to Advocate for Policy Change.” TOO proposal. June 2004. POLICY Project, Futures Group.
- “Reproductive Health of HIV-Positive Women in South Africa.” Desk review/rapid assessment. 2005. ICW.
- “Swaziland: Advocacy Training Programme on Access to Care, Treatment and Support, and Reproductive Health.” Desk review. 2005. ICW.
- “Advocacy Training Programme on Access to Care, Treatment and Support, and Reproductive Health.” Validation workshop report. June 13–15, 2005. Durban, South Africa. ICW.
- Training curriculum to increase HIV-positive women’s capacity to engage in policy dialogue and development related to promoting their reproductive health needs. November 2005.
- “Advocacy Training Programme on Access to Care, Treatment and Support, and Reproductive Health.” Workshop report. August 15–19, 2005. Durban, South Africa.
- Seven participant action plans. September 2005.
- “Advocacy Training Program on Access to Care, Treatment and Support, and Reproductive Health: Project Evaluation.” Draft. 2005. ICW/POLICY.
- “Meeting the RH Needs of HIV-Positive Women: Using Evidence to Advocate for Change.” TOO two-page summary included in report, *Targets of Opportunity: Activities and Achievements*. December 2005. POLICY Project.
- Synthesis report reviewing POLICY’s experiences promoting policy change and advocacy for improved HIV-positive women’s reproductive healthcare across countries, along with relevant literature on the current status of meeting HIV-positive women’s RH needs. Forthcoming, February 2006.