



Reproductive rights for women affected by HIV/AIDS?

A project to monitor Millennium Development Goals 5 and 6

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Ipas works globally to increase women's ability to exercise their sexual and reproductive rights and to reduce abortion-related deaths and injuries. We seek to expand the availability, quality and sustainability of abortion and related reproductive-health services, as well as to improve the enabling environment. Ipas believes that no woman should have to risk her life or health because she lacks safe reproductive-health choices.

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ABBREVIATIONS

ART	Antiretroviral therapy
ARV	Antiretroviral drug
CBO	Community-based organization
CCM	Country Coordinating Mechanism of the Global Fund
CD4	Type of blood cell that fights infection; levels of CD4 cells are used to determine progression of HIV infection
CEDAW	Convention on the Elimination of All Forms of Discrimination Against Women
CHANGE	Center for Health and Gender Equity
CSW	United Nations Commission on the Status of Women
EC	Emergency contraception
FEIM	Fundación de Estudio e Investigación de la Mujer
GAF	Gender AIDS Forum
GIPA	Greater Involvement of People Living with HIV/AIDS
Global Fund	Global Fund to Fight AIDS, Tuberculosis and Malaria
ICPD	International Conference on Population and Development
ICW	International Community of Women Living with HIV/AIDS
IEC	Information, education and communication
IPPF	International Planned Parenthood Federation
IUD	Intrauterine device
KDHS	Kenya Demographic Health Survey
LAPCA	Lesotho AIDS Programmes Coordinating Authority
LLPA	Lesotho Planned Parenthood Association
MDG	Millennium Development Goal
NGO	Nongovernmental organization
PECAC	Punto de Encuentro de la Comunidad, A.C.
PEP	Post-exposure prophylaxis
PHA	Persons living with HIV/AIDS
PPT	Prevention of perinatal transmission of HIV
PSI	Population Services International
STI	Sexually transmitted infection
TOP	Termination of pregnancy
UN	United Nations
UNAIDS	The Joint United Nations Programme on HIV/AIDS
UNFPA	United Nations Population Fund
USAID	United States Agency for International Development
VCT	Voluntary HIV counseling and testing
WHO	World Health Organization
WOFAK	Women Fighting AIDS in Kenya

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- International Centre for Reproductive Health, Mombasa
- Ministry of Education, Science and Technology – AIDS Control Unit, Nairobi
- Movement of Men Against AIDS in Kenya – Nairobi
- The Nairobi Women's Hospital
- National Organization of Peer Educators
- National Empowerment Network of People Living with HIV/AIDS
- Marie Stopes Kenya
- Society of Women with AIDS in Kenya – Nairobi

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EXECUTIVE SUMMARY

In the year 2000, the United Nations General Assembly adopted a declaration in which they proposed to make measurable progress toward the development of all nations by the year 2015. They delineated eight Millennium Development Goals (MDGs) to be achieved, two of which are very relevant for the reproductive health of women affected by HIV/AIDS:

- MDG 5 aims to improve maternal health by reducing the maternal mortality ratio by 75%.
- MDG 6, which focuses on combating HIV/AIDS, malaria and other major diseases, has a target of not only halting, but also reversing, the spread of HIV/AIDS and other diseases.

To make MDGs 5 and 6 more relevant to the daily work of organizations working for the benefit of women affected by HIV/AIDS, Ipas took the lead in a partnership that developed a resource called *Fulfilling reproductive rights for women affected by HIV: A tool for monitoring achievement of Millennium Development Goals*. The monitoring tool suggests benchmarks that can be used to assess steps along the path toward achieving MDGs 5 and 6.

In 2005, six organizations partnered with Ipas in trying out the monitoring tool as a data-collection method: Fundación de Estudio e Investigación de la Mujer (FEIM) did so in Argentina, the Gender AIDS Forum in South Africa, the International Community of Women Living with HIV/AIDS (ICW) in Lesotho and Swaziland, de Encuentro de la Comunidad, A.C. (PECAC) in Mexico, and Women Fighting AIDS in Kenya (WOFAK).

Each partner prepared its own project report and disseminated their findings independently. Ipas then prepared this report, which summarizes the overall project, describes how the monitoring tool was used and outlines the main findings presented by the individual organizations. This report concludes with recommendations regarding use of the monitoring tool and the particular needs that must be addressed in fulfilling the reproductive rights of women affected by HIV/AIDS. This Executive Summary summarizes the main findings and provides the recommendations endorsed by the project partners.¹

Project contexts and methodologies

Contexts: The contexts in which the country projects were carried out differ but also show some similarities. Three projects were carried out in countries with relatively moderate HIV/AIDS epidemics — Argentina, Mexico and Poland — while four projects took place in countries with advanced epidemics — Kenya, Lesotho, South Africa and

¹ Bibliographic references are included in the main text of the report.

Swaziland. The percentage of women being infected with HIV has risen in all these countries over recent years but it is in the African countries that women constitute more than 50% of people living with HIV/AIDS. It is also in the African countries that the numbers of children who have lost parents to AIDS are extremely high.

In all the project countries, women often find their decisionmaking capacities in the domestic and public spheres restricted by gender-based societal norms. Domestic violence and sexual violence against women is a major public-health problem in all seven project countries.

Methodologies: Some of the project partners chose to concentrate solely or mainly on women living with HIV as respondents for data collection, while others chose a range of respondents that included some women living with HIV/AIDS. A few projects assessed the national situation, since they had respondents from different parts of the country; others focused on certain municipalities and provinces.

The project description contained suggestions for different possible data-collection methods: interviews, facility visits and observations, mystery client visits to health facilities, document collection and review, and review of referral records.

Almost all the project partners gathered most of their information using oral or written surveys comprising sample questions provided by Ipas. FEIM, GAF and ICW adapted the questions slightly for their various categories of respondents. Four projects — GAF in South Africa, ICW in Lesotho and Swaziland and WOFAK in Kenya — also organized focus-group discussions with respondents.

All the partner organizations reviewed documentation related to HIV/AIDS policies, laws, regulations and programs within their countries, as well as a selection of information, education and communication (IEC) materials (including some they had produced themselves). They were asked to give respondents a copy of the *Barcelona Bill of Rights*, which was formulated by representatives of international and national organizations at the 2002 International Conference on AIDS in Barcelona, Spain. This document delineates the human rights that must be respected and fulfilled for women affected by HIV/AIDS if the world is to achieve a gender-equitable response to the AIDS pandemic.

To keep the project manageable within a short timeframe and to ensure that all partners covered similar topics, each organization was asked to assess 10 benchmarks from the monitoring tool. The issues about which information was collected can be grouped into six main categories:

- The availability of two specific measures to help women prevent HIV transmission: voluntary HIV counseling and testing (VCT) outside the antenatal care setting and provision of post-exposure prophylaxis (PEP) to survivors of sexual assault

- Fertility regulation, including access to contraceptive information related to the context of HIV infection, access to a range of contraceptives, and the availability of emergency contraception (EC) and safe abortion services
- Parenting options for persons living with HIV, including assisted conception (such as sperm washing and in-vitro fertilization), prevention of perinatal transmission of HIV (PPT), and legal adoption
- HIV/AIDS-related stigma and discrimination within the reproductive-health sector
- The use of human-rights documents as a framework for the provision of HIV/AIDS and reproductive-health programs and services
- The involvement of women living with HIV/AIDS in reproductive-health policy and program formulation, implementation, monitoring and evaluation

Key project findings

AVAILABILITY OF VCT AND PEP

Two prevention tools that are important in helping women avoid HIV infection are VCT and PEP. Although it might be assumed that the respondents in the various projects would be well-informed about HIV/AIDS issues such as VCT and PEP — especially because many HIV-positive and other respondents are educators and service providers — it became apparent that many of them lacked pertinent knowledge.

The World Bank has noted that achievement of MDG 6 will depend partly on ensuring access to VCT. Ideally, women should be enabled to learn whether they are HIV-positive or not at a time of their choosing and not only when they are pregnant. Expansion of VCT to reach women outside the antenatal care setting is therefore of great importance, particularly since counseling before pregnancy can help HIV-positive women consider their options for safer pregnancy and parenting and HIV-negative women consider their options for protecting themselves against transmission.

According to many respondents, VCT centers are becoming available in most large urban centers, but access to VCT in rural areas still leaves a great deal to be desired in some countries. Respondents in Poland and Swaziland noted that many women seem to be dissuaded from having an HIV test because they assume that they are not at risk — because they are a faithful spouse or don't belong to one of the "risk groups" highlighted in AIDS prevention messages — or because they are afraid of the consequences should others learn of their positive HIV status. As a consequence, it appears that many, if not most, women in the project countries still only learn of their HIV-positive status after antenatal testing.

Sexual violence against women is a pervasive problem worldwide; if a perpetrator of assault is HIV-positive, there is a definite chance of transmission, particularly if the victim is wounded during the attack. This has been recognized by some governments

through policies that aim to ensure that survivors of rape are offered PEP if they report the crime soon enough to benefit from this form of antiretroviral treatment.

Provision of PEP for survivors of sexual assault appears to be a relatively rare occurrence in all the project sites except South Africa. While some respondents thought PEP might be available for rape victims, almost none mentioned knowing of women who had actually used it and the project partners were unable to obtain any registered data on PEP provision related to sexual assault.

While the South Africa project did not discuss PEP availability — since their respondents were almost all already HIV-positive — they did note that new types of violence against women living with HIV are being perpetrated by their male partners: breaking condoms so that women cannot protect themselves against reinfection and pregnancy, and appropriating the women's ART supplies so that they cannot benefit from treatment.

In some project countries, PEP is available to health (and other) professionals who suffer occupational exposures to HIV; in others, PEP may be named in health regulations but not actually accessible. In almost all cases, it does not appear that good statistics are available on how many health professionals have accessed PEP.

FERTILITY REGULATION IN THE CONTEXT OF HIV/AIDS

Since the year 2000, an increasing number of agencies around the world have called for better collaboration between family-planning and AIDS programs because avoiding pregnancy can help reduce perinatal transmission rates. In this context, it is important that women living with HIV be informed on issues related to contraceptive methods and HIV/AIDS (such as possible interactions between hormonal contraceptives and drugs used to treat opportunistic infections); that they retain the right to make informed decisions about contraceptive use (that is, not be forced to use contraceptive methods controlled by health-care providers, such as injectables); and that they be enabled to access various options to regulate their fertility, including ways to deal with failed contraception.

Women's access to general information about family planning and contraceptive supplies appears to vary between and within the countries where the projects took place. Family-planning associations and governmental reproductive-health programs often have non-HIV-specific printed materials available, and access to supplies in urban areas is fairly good (with Argentina and Poland as exceptions). However, the range of contraceptive options can be limited and little information appears to be available regarding contraception in the context of HIV infection. In essence, the projects found that health-care providers' preferences still determine how much and what kind of information women receive about contraceptives. When family planning is discussed

with women living with HIV/AIDS, emphasis continues to be placed on use of the male condom.

Reports have emerged in recent years that some ART programs may require women to use provider-defined contraceptive methods in order to be eligible for treatment. Some focus-group respondents in Kenya mentioned that they are asked to use condoms, and health-care providers in Mexico said they also promote condom use because it can help prevent infection with new strains of HIV. It was only in Lesotho that one HIV-positive woman said she had been asked to use either injectables or an intrauterine device (IUD) so that her health-care providers could supervise her fertility control. Women in Poland are asked to tell their physicians when they become pregnant so that their ART regimens can be changed if needed (a few antiretrovirals are contraindicated for pregnant women).

Knowledge of and access to emergency contraception (EC) is still limited in the areas assessed by the projects. In some cases, there is active opposition to making it more widely available (such as in Argentina and Poland), while in other places bureaucratic and financial factors impede increased availability within the health sector.

The topic of abortion — or even postabortion care — appeared to be avoided by respondents in Argentina, Kenya and Poland. A few health-care professionals in Mexico spoke about abortion being taboo and illegal, even though it is permitted in the state of Quintana Roo in cases of rape, fetal malformation and danger to a woman's health. Respondents in Lesotho and Swaziland mentioned that some women travel to South Africa for legal abortions. The Swazi women expressed concern about a lack of postabortion care services in rural areas and were further troubled by reports of abandoned babies and infanticide by women who could not cope with having children from unwanted pregnancies. Even in South Africa, which has liberal legal indications for termination of pregnancy, the HIV-positive respondents noted that women are dissuaded from accessing abortion services and may suffer abuse if they are able to obtain this legal medical procedure. Reports of such abuse included being handed a fetus for disposal and being "granted" a termination of pregnancy (TOP) only after agreeing to be sterilized.

PARENTING OPTIONS FOR HIV-POSITIVE WOMEN

In recent years, considerable attention has been paid to childbearing by women living with HIV/AIDS. The focus has been mainly twofold: supporting women's right to bear children by combating forced or coerced sterilization and abortion and preventing perinatal transmission of HIV. Very little attention has been given to other issues related to parenting such as the availability of assisted conception methods and legal adoption by HIV-positive people.

At least some respondents in Kenya, Lesotho and Swaziland said they knew of HIV-positive people who had adopted children; it was unclear whether the children were also HIV-positive. In Poland, one NGO is actively mediating so that such adoptions can take place, although here it seems that only children who are themselves HIV-positive are placed with adults who are living with HIV. In Mexico, governmental regulations prohibit adoption by seropositive persons.

In the projects that touched on the issue of assisted conception, the respondents indicated that this option was scarcely available to people living with HIV; only one case in Poland was mentioned where a couple was able to make use of assisted reproductive technology.

HIV/AIDS-RELATED STIGMA AND DISCRIMINATION

The persistence of HIV/AIDS-related stigmatization over the course of the pandemic has led to increasing efforts to examine how stigma affects prevention and treatment efforts and how it might be tackled. Some approaches to combating stigma are showing success, so we were interested in determining whether stigma and discrimination are still recognized as problems.

The project showed that although we have passed the 20-year mark for the worldwide HIV/AIDS pandemic, considerable numbers of health-care professionals still have insufficient information about HIV/AIDS and their risks of occupational exposure to HIV infection. This is contributing to fear and subsequent stigmatization and discrimination in the health-care sector of patients and clients living with HIV.

While some respondents (and project data collectors) knew of health facilities that provide high-quality care, all the projects reported that stigma and discrimination against women living with HIV/AIDS persist within the health-care sector. The extent to which this still takes place may be much greater than is often assumed, particularly as some HIV-positive researchers were surprised and sometimes shocked at the examples of abuse reported.

Many types of discrimination are remarkably similar across countries and regions. HIV-positive women in Africa, Europe and Latin America are facing denial of treatment and care, humiliating and stigmatizing attitudes, and breaches of confidentiality. This is particularly the case among health professionals who are not specialized in HIV/AIDS care. The South African project noted a new type of discrimination that is taking place: using women's participation in clinic-based ART support groups as a precondition for granting treatment.

"At the onset of the research, we were realistic about the state of the health-care system and based on our own experiences, and that of women and girls we knew, we were aware of the negative treatment women suffered at the hands of the health-care worker. However, the realities of what we heard and saw were far worse than we imagined... As researchers, women and activists, we felt sad, depressed and deeply concerned about the experiences of women living with HIV and AIDS. We found it difficult to deal with the depths of grief and pain experienced by women, their lack of knowledge and access to any rights..."

We were shocked at the lack of apparent knowledge about HIV/AIDS and other issues of the health-care workers. Why, after 20-plus years of an epidemic, are women and men treated so badly? Why are women's lives so difficult? How does the system that is supposed to be about 'health' and 'care' work so strongly against our wellbeing? As researchers, we feel and understand that we have a responsibility to all women who are trying to access sexual and reproductive health and rights. We have a responsibility to the women whom we interviewed in particular, to ensure that the issues raised in this project do not remain only in this document. We are committed to take the issues forward so that they are listened to, believed and acted upon at both a policy and practice level."

— Gender AIDS Forum

Particularly troubling is the fact that discrimination is often reported regarding obstetrical and gynecological care. Given the enormous amount of attention paid to PPT programs in the last five years, we might have expected that human-rights violations in this area of health-care would have become minimal. It is perhaps the continuing emphasis on PPT rather than comprehensive care for pregnant women that has contributed to this situation. If this focus continues, we may face more cases of rights violations in the context of opt-out testing, which is being heavily promoted for antenatal care in many countries. While women theoretically should be able to decide freely to refuse routinely offered HIV tests, human-rights scholars and activists are warning that opt-out systems may easily turn into systems that impose HIV tests since many patients are reluctant to challenge advice or instructions from health-care providers. Issues that require attention in this area include obtaining truly voluntary and informed consent, safeguarding confidentiality and ensuring proper counseling for women to be tested.

HUMAN RIGHTS AS A FRAMEWORK FOR PROVISION OF PROGRAMS AND SERVICES

A basic premise underlying the monitoring tool is that awareness of sexual and reproductive rights is essential for achieving the MDGs and for providing women living with HIV/AIDS with comprehensive health care. International human-rights conventions have established that all people have a right to health and health care. All countries that are members of the United Nations (UN) have endorsed at least one human-rights treaty

that refers to the right to health; therefore all UN member States are obliged to respect, protect and fulfill this right.

For example, to realize the right to health care, women should be enabled to discuss treatment with their health-care providers and to decide what kind of treatment to receive after being fully informed about the benefits and drawbacks of various options. With the advent of ART, projects are being carried out on “treatment literacy” in various countries, wherein patients are educated about antiretroviral drugs — types of drugs available; when, how and why they are administered; possible side effects; drug resistance; and so on. It is very often associations of people living with HIV who carry out such educational efforts, with support from UN agencies such as the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO).

The right to health care is also being referenced in relation to the MDGs. Numerous UN, governmental, intergovernmental and nongovernmental agencies have issued background documents about how to achieve the MDGs in preparation for a World Summit to be held in September 2005. A recurring theme in many of their documents is that the MDGs will not be achieved unless all people are enabled to receive services related to their sexual and reproductive health.

The right to health has further been established in the constitutions or laws of countries around the world. It follows that people affected by HIV/AIDS and health-care providers need to be aware of the right to health and the corresponding obligation of health systems to provide care and treatment. They also need to know that violations of this human right can be reported so that people who are denied proper care can seek fulfillment of their rights through national and international legal systems. Women affected by HIV/AIDS and health-care professionals should be familiar with international and national documents that explain sexual and reproductive rights, such as the *Barcelona Bill of Rights* and the *International Guidelines on HIV/AIDS and Human Rights* issued by the Office of the United Nations High Commissioner for Human Rights and UNAIDS.

Familiarity with the *Barcelona Bill of Rights* was limited in all of the project countries, although respondents expressed interest in the document and the institutional representatives said they were willing to display or otherwise make available a copy for their clients. Though some health-care providers said they knew of the international guidelines on HIV/AIDS and human rights, it was not always clear if they were referring specifically to the guidelines produced by UNAIDS and the UN High Commissioner for Human Rights.

The collected data indicated that that while national government programs and hospital regulations may endorse rights, this does not automatically translate into observance of those rights at the service-delivery level. Compliance with rights depends on

enforcement by provincial and municipal authorities, funding for programs (which affects availability of supplies, equipment and sufficient staff), and positive attitudes and willingness on the part of service providers.

The large majority of respondents in all countries were interested in receiving more information about rights. However, both health-care providers and women living with HIV/AIDS did not seem clear on how such documents could be relevant to their work environments and daily lives.

In South Africa, where treatment-literacy programs have been widely promoted so that women living with HIV become empowered to act on behalf of their own health, some women have been insulted for knowing and understanding their needs and the correct options for their treatment. Health-care workers often don't have this information themselves or feel threatened by a treatment-literate community.

Health-care workers are regarded with great respect by women and other community members. They are expected to be responsive to the needs of the community. When they fail to do this or when they act in ways that contradict their caring role, community members are either unable to consciously identify this as a violation of their rights or are seldom able to assert their rights (for example, through direct communication with the health-care provider or by initiating a complaints procedure). Women especially are likely to feel subservient to health-care workers and unable to assert themselves since they often occupy a subordinate position in society. Women living with HIV/AIDS are in an even more complex situation when they are stigmatized and marginalized by society, including by health-care providers.

INVOLVEMENT OF HIV-POSITIVE WOMEN IN REPRODUCTIVE-HEALTH POLICIES AND PROGRAMS

The GIPA Principle — Greater Involvement of People Living with HIV/AIDS — was adopted by UNAIDS and other UN and nongovernmental agencies because they recognized that measures to tackle HIV/AIDS will not succeed unless the people most directly affected by the pandemic are fully involved in all aspects of programs. This was reiterated at the high-level UN General Assembly session in June 2005 to review progress in combating HIV/AIDS.

Gender-based analyses of efforts to improve sexual and reproductive health have further asserted that women must be enabled to participate in policymaking and other decisionmaking if any success is to be achieved. It follows that women affected by and living with HIV/AIDS must therefore be involved in decisionmaking regarding reproductive-health policies and programs.

Some formal mechanisms exist through which women affected by and living with HIV/AIDS are granted a place on decisionmaking bodies, but respondents in all

countries indicated that this involvement often continues to be tokenistic. They also asserted that many women lack the skills and back-up support needed to be effective advocates in such bodies. The women living with HIV in Argentina, Lesotho, Poland and Swaziland in particular commented on the corresponding need for capacity-building in this area.

On the whole, the project results indicated that women living with HIV/AIDS are **not** involved in policy and program formulation, design and evaluation at the local or national levels. When respondents spoke of HIV-positive women's involvement in programs, they invariably referred to women helping implement programs and services. Time and again, the women themselves, representatives of government agencies and NGOs, and health-care providers acknowledged the valuable contributions of HIV-positive people — usually as volunteers — to prevention activities, counseling, community support, home-based care and, more recently, ART treatment support. In reality, the GIPA principle is interpreted to mean “a greater role for people living with HIV/AIDS in delivering services.”

Recommendations

Expand and intensify training for health professionals on occupational risks of HIV infection in conjunction with capacity-building on the rights of people living with HIV/AIDS. Such training should emphasize that health-care providers have a right to have sufficient supplies available — such as gloves, disposable needles and sharps disposal boxes — to observe universal precautions for themselves and their patients. Health systems must also make PEP available to providers.

Training sessions and workshops on the ethics of service provision to people living with HIV should incorporate HIV-positive women as paid facilitators since guided dialogues between them and providers can contribute to changes in attitude and subsequent treatment of clients and patients. HIV-positive women who have had treatment-literacy training can help explain why it is important for patients to be partners with health professionals in treatment implementation.

Employ women living with HIV in prevention and VCT programs as paid staff. Many programs involve HIV-positive women (and men) in disseminating prevention messages — use condoms, get tested, be faithful to your partner — through talks and personal appearances during educational activities. However, it does not seem that women living with HIV are often consulted regarding the kinds of messages that would have drawn their attention before they learned their serostatus. For example, what messages might have motivated them to have an HIV test sooner than they did? Involving HIV-positive women in the formulation of prevention policies and messages is very important and they should be paid for providing their life-based expertise and input.

One factor impeding the establishment of more VCT sites throughout countries is a lack of trained counselors. Many health-care professionals already have heavy workloads for meager wages and may be reluctant or unable to add counseling to their daily tasks. Trained HIV-positive persons have proved to be excellent counselors in many countries. Health systems need to stop relying on them as volunteers; rather, they should be employed as health-system staff so that services become more widely available.

Prepare and publish materials on family planning, contraception and options for avoiding and dealing with unwanted pregnancies in the context of HIV/AIDS. While it is reasonable for women living with HIV to be informed about the double protection against reinfection and pregnancy offered by male condoms, they also should receive more information about other contraceptive options.

Such information should address concerns related to HIV/AIDS, such as which contraceptives might be preferable for women in their situation and what the potential interactions are between hormonal contraceptives and drugs for opportunistic infections and ART. Options for avoiding unwanted pregnancies should also be mentioned, including EC and safe abortion for indications considered lawful in each country. Given the high prevalence of sexual violence experienced by women living with HIV, for example, it is important that they know whether pregnancy termination is allowed in cases of rape or when a woman's health is endangered.

While such materials can be developed through collaboration between governmental AIDS and reproductive-health/family-planning programs, NGOs can also play a role .

Advocate for increased availability and accessibility of EC, PEP and safe, legal abortion. Both governmental agencies and NGOs need to ensure that HIV-positive women and men are informed about all the available options that can help protect against HIV reinfection and unwanted pregnancy. Information provision alone is not enough, however: women's awareness and understanding of their rights will be meaningless if services are not available. Lobbying and advocacy on these issues with NGOs, through the media and toward policymakers is an important step toward expanding women's options to exercise their rights to health and to decide whether and when to have children.

Advocate and lobby for the possibility of HIV-positive women and men adopting children. While women living with HIV can reduce the chances of HIV transmission by participating in PPT measures, they can also avoid perinatal transmission by not becoming pregnant at all. Many HIV-positive women, particularly younger women, do indeed want to become pregnant and bear biological children. However, some women are interested in adopting children and this option should be possible.

Organizations working on AIDS should ascertain whether legal restrictions on adoption would prevent HIV-positive people from adopting and, if so, whether these restrictions are reasonable. NGOs and government agencies entrusted with adoption programs should collaborate with associations of people living with HIV to discuss how programs can ensure that HIV-positive people are not automatically disqualified as prospective adoptive parents because of their infection. Adoption as a parenting option should be included in informational materials on sexual and reproductive health for people affected by HIV. Associations of people living with HIV can also begin disseminating stories about successful adoptions through newsletters, websites and conferences; cases from one country can serve as examples and inspiration for people in other countries.

Disseminate information on human-rights standards in practical terms relevant to recipients' work and lives. Informing people affected by and living with HIV, service and health-care providers, NGO staff and policymakers about sexual and reproductive rights in the context of HIV/AIDS is a sorely needed intervention in many countries.

Disseminating documents such as the International Planned Parenthood Federation's summary guide to sexual and reproductive rights, the *Barcelona Bill of Rights* and the *International Guidelines on HIV/AIDS and Human Rights* — as well as locally produced materials on human rights — is an essential and fairly simple step to take. It does depend on the willingness and financial capacity of advocates to obtain, translate, reproduce and distribute the documents to all parties concerned. If funds are limited, such documents can at least be photocopied to leave as display copies with NGOs, in waiting rooms of governmental agencies, and at VCT sites, hospitals and clinics.

Mere dissemination of human-rights documents is nevertheless insufficient to help people understand how these rights apply to their lives. They need to understand which international rights treaties their government has ratified, how those rights can be claimed through laws and regulations (which requires lobbying lawmakers), and how private citizens can bring forward complaints when their rights are violated. NGOs need to help HIV-positive women identify where complaints can be addressed and provide them with support in following up on those complaints, which can be a lengthy process. This can include instructing HIV-positive women about how to lodge complaints with hospital and clinic directors, how to submit cases for follow-up with local human-rights commissions and ombudsmen, and how to find lawyers who can take well-documented cases to court if necessary.

Pressure can also be put on governments to speed up compliance with human-rights treaties by preparing reports for the international committees that monitor treaty compliance; such reports can come from individual citizens and NGOs. Associations of people living with HIV/AIDS and NGOs can also lobby the individuals and institutions

that should be accepting complaints about human–rights violations to actually deal with those cases in a timely fashion.

Information about these measures can be disseminated through articles in newsletters and journals, through brochures and leaflets, and through capacity–building sessions for both service providers and clients/patients. When people understand that there are practical steps they can take regarding discrimination and rights violations, these rights can leave the realm of theory and enter into the reality of daily life.

Promote capacity–building and skills–building for women affected by and living with HIV/AIDS so that they can participate meaningfully in advocacy and policymaking. Many of the women who have direct experience with the HIV/AIDS epidemic and could contribute invaluable information to inform and direct policies and programs have had no formal training on translating that experience into advocacy and action. The projects indicated that women want a place at the decisionmaking table but that this must be achieved in a meaningful way so that their voices are actually taken into account in the development of policies and programs.

NGOs and universities can provide a wealth of information on advocacy and policymaking strategies and procedures, and can contribute greatly to enhancing women’s skills. One way is to engage more HIV–positive women in gathering information and evidence on which advocacy and community action can be based — similar to what was done in the projects in Kenya and South Africa, where the research teams included women living with HIV. The respondents in Swaziland also recommended that HIV–positive women be more involved in designing research studies and evaluating what can be done with the findings.

In addition to the training courses and workshops on advocacy and policymaking that are usually recommended, another approach to explore is mentoring. More university and NGO staff can offer women living with HIV a chance to collaborate on their research as interns, with a clearly stated objective of the women gaining skills to use in other capacities. NGOs can mentor and guide women in developing skills such as proposal writing, program design, strategic planning, documentation of program achievements, and monitoring and evaluation.

As the respondents in Swaziland noted, capacity–building also needs to be a two–way process so that governments, businesses and organizations learn how to create meaningful involvement of women affected by and living with HIV/AIDS. Asking HIV–positive women to cofacilitate such capacity–building would be a step in the right direction.

Conclusion

The project showed that providing the monitoring tool on HIV, reproductive health and MDGs 5 and 6 as a framework, together with some very simple guidance on implementing a data-collection exercise, was sufficient to enable partners in very different countries to collect information on the same topics. The project presented the staff of some partner organizations with their first opportunity to engage in a simple research/data-collection exercise. The country coordinators and project teams appreciated their involvement in the project and all expressed willingness to repeat the exercise at the end of 2005.

As well as the project team members, respondents also found this to be a valuable exercise for themselves and their organizations, a considerable number saying that the exercise had opened their eyes to issues they had not yet thought about but which are nevertheless important. It even motivated some respondents to begin undertaking their own research to increase their knowledge about the various issues raised — which was precisely one of the project goals.

The data collected by the different projects using the monitoring tool showed that much remains to be done if MDGs 5 and 6 are to be realized. If maternal mortality is to be reduced, women need to be able to make fully informed decisions about pregnancy and parenting. This means they need relevant and specific information on contraceptive methods and all their fertility-regulation options, including ways to avoid and end unwanted pregnancies, such as EC and safe, legal abortion. They need to know whether assisted conception is available and what else they can feasibly do to have safer pregnancies. People living with HIV also need to know whether legal adoption can help them fulfill their parenting desires.

If HIV/AIDS is to be combated in a meaningful way, more attention must be paid to prevention measures relevant for women. For example, given the high levels of violence against women that still exist around the world, PEP must be made available for survivors of sexual assault. Women can be encouraged to access VCT through prevention messages that focus on everyone's vulnerability to infection, not only that of "risk groups." VCT sites must be rapidly expanded, especially to more rural areas, and HIV-positive women must be involved as co-managers, counselors and evaluators of these services to help improve their quality and relevance for other women.

One of the most important interim MDG benchmarks to be accomplished is eradicating HIV/AIDS-related stigma and discrimination. Our respondents' experiences indicate that much more must be done to promote positive attitudes, reduce fears and educate people on how they — even unconsciously — sustain stigma and discrimination. Progress in this area will undoubtedly support and enhance all other efforts to improve the sexual and reproductive health of people vulnerable to and living with HIV/AIDS.

1. PREFACE

In the year 2000, the United Nations General Assembly adopted a Millennium Declaration in which they proposed to make measurable progress toward the development of all nations by the year 2015 [1]. They delineated eight Millennium Development Goals (MDGs) to be achieved. While none of these goals directly address sexual and reproductive health in broad terms, two of them are very relevant for the reproductive health of women affected by HIV/AIDS:

- MDG 5 aims to improve maternal health by reducing the maternal mortality ratio by 75%.
- MDG 6, which focuses on combating HIV/AIDS, malaria and other major diseases, has a target of not only halting, but also reversing, the spread of HIV/AIDS and other diseases.

The MDGs are quite ambitious, and only measuring achievement of their named targets does not provide any indication of interim progress. To make MDGs 5 and 6 more relevant to the daily work of organizations working for the benefit of women affected by HIV/AIDS, Ipas therefore took the lead in a partnership that developed a resource called *Fulfilling reproductive rights for women affected by HIV: A tool for monitoring achievement of Millennium Development Goals* [2]. The monitoring tool suggests benchmarks that can be used to assess steps along the path toward achieving MDGs 5 and 6.

In 2005, six organizations partnered with Ipas in trying out the monitoring tool as a data-collection method. They included organizations of women living with HIV/AIDS, a family-planning association, and nongovernmental organizations (NGOs). These organizations and the countries in which they piloted the tool were:

- The Federation for Women and Family Planning (hereafter referred to as the Federation), an affiliate of the International Planned Parenthood Federation in Poland [3].
- The Foundation for Studies and Research on Women (FEIM), an NGO that works on sexual and reproductive health in Argentina [4].
- The Gender AIDS Forum (GAF), an NGO working on gender and HIV and AIDS issues in South Africa [5].
- The International Community of Women Living with HIV/AIDS (ICW), the only international network exclusively representing HIV-positive women and girls, which used the tool in Lesotho and Swaziland [6].
- Punto de Encuentro de la Comunidad, A.C. (PECAC), the only NGO working on HIV/AIDS in Chetumal, the state capital of Quintana Roo, Mexico [7].
- Women Fighting AIDS in Kenya (WOFAK), an association that provides counseling, training and material support to women living with and affected by HIV/AIDS [8].

Each partner prepared its own project report and disseminated their findings independently. This report summarizes the overall project, describing how the monitoring tool was used and presenting the main findings presented by the individual organizations. It concludes with recommendations regarding use of the monitoring tool and the particular needs to be addressed in fulfilling the reproductive rights of women affected by HIV/AIDS.

2. INTRODUCTION

2.1. DEVELOPMENT OF THE MONITORING TOOL

On 8 March 2004, 25 national and international organizations submitted a statement to the secretariat of the UN Commission on the Status of Women (CSW) to draw attention to areas of reproductive health that are neglected with regard to HIV-positive women [9]. These areas include fertility regulation, motherhood and gynecological care.

To extend the impact of this statement beyond the CSW session itself, representatives of four organizations — Ipas, the International Community of Women Living with HIV/AIDS (ICW), the Pacific Institute for Women's Health, and the Center for Health and Gender Equity (CHANGE) — used the statement to develop a practical tool to help NGOs and community-based organizations (CBOs) assess and monitor whether progress is being made toward fulfilling the reproductive rights of women affected by HIV/AIDS [2].

We related the tool to the MDGs because, after the year 2000, that framework became the focus for development work and assistance at the international level. The MDGs do not include a broad sexual- and reproductive-health goal and MDG 3, on promoting gender equality and empowering women, also fails to mention sexual and reproductive health and rights. However, the UN Secretary General has stated that ensuring access to sexual- and reproductive-health services promotes development since it advances gender equity and empowers women [10]. The World Bank has added that development assistance to improve health status and health care is only significantly effective when given in a context of good policies and institutions [11]. In our view, such an environment includes policies and institutions that promote respect for, and fulfillment of, sexual and reproductive rights for all people, including those living with and affected by HIV/AIDS. Others, such as the European Union, NGOs and international reproductive-health experts, support that viewpoint [12-14].

2.2. AIMS FOR USE OF THE MONITORING TOOL

It is our hope that use of the monitoring tool can fulfill four aims. First, we want to provide groups that have no formal or extensive research capacity with a simple means of collecting information on the aforementioned issues. Many NGOs and CBOs are unable to conduct large-scale baseline and follow-up surveys and therefore are not in a position to generate statistically valid and generalizable data. Nevertheless, many organizations can conduct rapid assessments and monitor changes in policies, programs and services using simple benchmarks and accompanying questions to identify which aspects of reproductive health are being addressed.

Second, we want to show how two of the MDGs — MDG 5 on reducing maternal mortality and MDG 6 on halting the spread of HIV/AIDS — can be made more pertinent

to the daily reality and work of individuals and organizations at the local level. The MDGs were formulated primarily to reflect national-level goals; relatively few NGOs and CBOs can show how their work is helping to reduce maternal mortality by 75% or stopping the spread of HIV. However, benchmarks that represent steps toward achieving those targets can be related more directly to the work of many organizations. For example, NGOs that advocate for and/or provide EC without a prescription or as a prophylactic measure are contributing to contraceptive use, which in turn lowers the number of potential HIV-positive births.

Third, we hope that use of the monitoring tool will contribute to the knowledge base and skills with which NGOs undertake advocacy and other efforts to influence policy, research and program agendas in their localities. Most research and data collection regarding policies, programs and services is conducted by formally trained researchers; the involvement of people who use and benefit from those policies, programs and services is limited or nonexistent. We want to enable NGOs, CBOs and people living with HIV to participate in collecting and analyzing data and proposing recommendations on further developments in the field of HIV/AIDS and reproductive health.

“User involvement in research is not just about making the interviews more user-friendly to the research participants (although this is an area where evidence does support the advantage of involving service users); it is also about questioning some of the philosophical foundations for the research itself. It is not enough to invite a user to sit on an advisory group. Researchers need to acknowledge the change in ethos that this represents and to understand that we, as service users, have access to some specialist knowledge and views that may be valuable in the conduct of the research” [15].

We envision that the project reported on here will help raise awareness about the unmet reproductive-health needs of women affected by HIV/AIDS and hopefully contribute to HIV/AIDS-related program planning and implementation, as well as to local and national efforts to achieve MDGs 5 and 6. Project partners each have a local report to share with others, in print or through their websites and e-mail forums; this can lead to further discussion and action on the issues concerned.

Finally, we hope that data on similar issues can be collected across time and across countries and regions for presentation at national and international venues where HIV/AIDS policies and programs are formulated and reviewed.

3. PROJECT BACKGROUND INFORMATION

3.1. PROJECT DESCRIPTION

Using personal contacts and information on potential partners gleaned from e-mail listserves, Ipas approached 10 NGOs to ask whether they would be interested in trying out data collection using the monitoring tool. We attempted to involve NGOs in countries with smaller and larger AIDS epidemics, and NGOs that specialize in AIDS work as well as those working on broader sexual- and reproductive-health issues.

Ipas contacted one international network (ICW) and NGOs in the following countries: Argentina, Kenya, Mexico, Namibia, Poland, South Africa, Thailand, Trinidad and Tobago, and Turkey. Those approached in Namibia, Trinidad and Tobago and Turkey expressed interest but ultimately were unable to fit the project into their ongoing activities. The Thai group began the project but ultimately did not deliver a report. ICW chose to participate by integrating the project into activities that they had already planned in Lesotho and Swaziland.

Ipas paid each partner US\$2,000 to help cover staff time, transportation, photocopying, postage and other logistical costs of the project. To keep the project manageable within a short timeframe and to ensure that all partners covered similar topics, each organization was asked to assess the following 10 benchmarks from the monitoring tool:

1. All relevant local government agencies and NGOs require programs serving HIV-positive women to include them in policy and program design.
2. All agencies serving local HIV-positive women publicly endorse documents listing their reproductive rights.
3. All women have access to family-planning information that addresses contraception in relation to HIV/AIDS.
4. All organizations serving HIV-positive women address all available legal options for preventing and avoiding unwanted pregnancy.
5. All women, including HIV-positive adolescents and adults, have easy and affordable access to emergency contraception.
6. Voluntary HIV counseling and testing (VCT) is available at women-centered health-care services besides antenatal and delivery care.
7. Women's choices on how to regulate their fertility do not prevent them from accessing antiretroviral therapy (ART).
8. Health care-based stigma and discrimination in relation to HIV/AIDS has been successfully eradicated.
9. Measures have been taken to minimize chances of HIV infection in women who have been subjected to coerced or forced sex, both within and outside marriage.

10. HIV-positive women and men are informed about all their legal options for parenting (including adoption).

Ipas provided ideas for possible data-collection methods, a sample questionnaire for interviews and a sample informed consent form for respondents to sign. The partner organizations were free to adapt the questions and to use other data-collection methods of their choice. Each partner was obliged to answer a set of questions relating to how the data collection was carried out, obstacles they encountered in trying out the tool, and suggestions on how use of the tool could be improved in the future.

3.2. PROJECT CONTEXT IN PARTNERS' COUNTRIES

The contexts in which the projects were carried out differed but also showed some similarities. Three projects were carried out in countries with relatively moderate HIV/AIDS epidemics — Argentina, Mexico and Poland — while four projects took place in countries with advanced epidemics — Kenya, Lesotho, South Africa and Swaziland. The percentage of women being infected with HIV has risen in all these countries over recent years but it is in the African countries that women constitute more than 50% of people living with HIV/AIDS. It is also in the African countries that the numbers of children who have lost parents to AIDS are extremely high.

In all the project countries, women often find their decisionmaking capacities in the domestic and public spheres restricted by gender-based societal norms. Domestic violence and sexual violence against women are major public-health problems in all seven project countries. For example, a demographic health survey published in Kenya in August 2004 estimated that more than 50% of women had suffered violence since the age of 15 years [16]. South Africa has one of the highest rates of rape in the world, with the Law Commission estimating 1.6 million occurrences annually [17].

Some of the project partners chose to concentrate solely or mainly on women living with HIV as respondents for data collection, while others chose a range of respondents that included some women living with HIV/AIDS. A few projects assessed the national situation since they had respondents from different parts of the country; others focused on certain municipalities and provinces. Some additional background information on the contexts in which the projects were carried out is presented below.

Argentina

According to the Argentine National AIDS Program, in September 2003, 26,832 persons living with HIV had been registered in the country — 75.8% were male and 23.7% female [18]. About 65% of HIV infections are found in the country's capital, Buenos Aires, and its immediate surroundings. In 2002, HIV prevalence among pregnant women was 0.4%, and the male-to-female ratio of people living with HIV fell from 15:1 in 1988 to 3:1 in 2002 [19]. Since 1997, the government has mandated that pregnant women must be

offered the chance to take an HIV test and to receive ART to prevent perinatal transmission if they are found to be HIV-positive [20].

Most people living with HIV/AIDS receive medical care through the public-health system, which provides treatment mostly to poorer people who do not have private or employer-funded health insurance [21]. Cases of AIDS and deaths due to AIDS have decreased since 1998 when viral load assays, ART and drugs to treat opportunistic infections became available free of charge through the public-health system as a result of a court case brought by FEIM and seven other NGOs. Nevertheless, some people have difficulty accessing or using ART because of bureaucratic requirements and long waiting times at hospitals and laboratories. Some patients are unable to meet their daily subsistence needs due to poverty; a lack of steady meals can affect ART regimens.

FEIM chose to carry out its project from February through May 2005 with a main focus on governmental agencies and NGOs in Buenos Aires City and Bahía Blanca, a city in Buenos Aires province. The NGO respondents also included people living with HIV/AIDS.

Kenya

The Kenya Demographic Health Survey (KDHS) 2003 revealed that 6.7% of adults tested are infected with HIV. Reconciliation of KDHS and sentinel surveillance data gives an adjusted prevalence rate of seven percent (with a range of 6.1 to 7.5%), implying that some 1.1 million adult Kenyans are infected with HIV; about two-thirds are women [22]. The gender difference is most pronounced among young people; prevalence among young women aged 15 to 24 years is nearly five times higher than that among their male counterparts. A study published in 2001 indicated that HIV infection rates were 10% higher for married than single women aged 15 to 19 years in Kisumu [19].

In addition, it is estimated that 100,000 children are living with HIV and that 1.7 million children under 18 are orphans, about half due to AIDS. There are now about 150,000 AIDS deaths per year, which is double the rate in 1998. The government and NGOs provide ART free of charge to at least some HIV-positive persons but patients may have to pay fees for viral load tests or CD4 counts.

WOFAK used its field offices in Kisumu, Mombasa and Nairobi to enlist mostly women living with HIV in the study. Some of them were working as civil servants, while others were employed by CBOs, NGOs and parastatal organizations. The project began in January 2005 and concluded in April 2005.

Lesotho and Swaziland

By the end of 2003, it was estimated that 300,000 adults had been infected with HIV in Lesotho; 170,000 were women aged 15 to 49 years [23]. Surveys have shown that up to two-thirds of young women aged 15 to 24 years cannot name three HIV prevention methods [19]; this undoubtedly contributes to the high rate of HIV prevalence among pregnant women, which was 27.8% in 2003 [24]. It has been further estimated that 100,000 children younger than 17 years have lost one or both parents to AIDS.

In Swaziland, 200,000 adults had contracted HIV by the end of 2003, including 110,000 women aged 15 to 49 years [25]. The Ministry of Health and Social Welfare found that the HIV prevalence rate among pregnant women increased from 38.6% in 2002 to 42.6% in 2004 [26]. Approximately 65,000 children up to the age of 17 years have lost one or both parents to AIDS.

In both Lesotho and Swaziland, ICW focused their data collection on the experiences of women living with HIV/AIDS. The respondents came from different parts of the two countries and were participants in workshops that examined the implementation, at the national level, of international declarations of commitment to address the rights of HIV-positive women. Women in the workshops completed questionnaires that included the topics of the monitoring tool; some of them also participated in a focus group held during the workshop. ICW also addressed some of the monitoring tool issues during other workshop sessions; the women's observations at those times also informed ICW's final report. The workshop in Swaziland took place from 30 January to 4 February 2005 and in Lesotho from 6–11 February 2005.

About half the women in each workshop came from rural areas. The participants were selected on the basis of criteria that included their experience of participation or activism around HIV and AIDS and/or gender issues, their understanding of the policy context relating to HIV and AIDS, their ability to engage with policy documents (written in English) and their grasp of advocacy issues.

Mexico

By the end of 2003, 160,000 adults had contracted HIV throughout Mexico, including 53,000 women aged 15 to 49 years [27]. HIV prevalence in the adult population ranged from 0.1 to 0.4% [28]. Quintana Roo is one of the states with the highest prevalence; in 2003, the rate was 0.55% [29]. While most HIV infections are found among men who have sex with men and injecting drug users, the Ministry of Health reports that heterosexual transmission is increasing [19].

PECAC carried out their project between 10 January and 29 March 2005 in the city of Chetumal and the larger municipality of Orthón P. Blanco in the Mexican state of Quintana Roo. (Chetumal, the state capital, is part of Orthón P. Blanco.) They interviewed women living with HIV, representatives of state agencies and staff of various health-care facilities.

Poland

Since 1985, when the first case of HIV infection was discovered in Poland, 9,342 HIV infections have been registered, with at least 5,213 infections being related to drug use. According to official data from the National Institute of Hygiene, approximately 25% of all adults living with HIV in Poland today are women of reproductive age [30]. The male-to-female ratio of new diagnoses steadily declined from 1:4.8 in 1987 to 1:2.9 in 1998. Nevertheless, women are still perceived to be at low risk and are less frequently informed about HIV testing [31]. Doctors are not obliged to offer HIV tests to pregnant women and other women of reproductive age. On average, women are diagnosed with HIV infection later in the course of the illness than men and their prognosis is consequently worse.

There is no registration of pregnancies among women living with HIV in Poland. Based on oral information gathered from doctors who provide care to HIV-positive mothers and their children, it can be estimated that there are about 200 to 220 HIV-positive women giving birth every year. The number of pregnancies that end in miscarriage or induced abortion is unknown, but some HIV-positive women interviewed for this project said they knew of peers who had had clandestine abortions (since termination of pregnancy is severely restricted in the country). In 2001, 23 women known to be HIV-positive were receiving ongoing antenatal care; 19 of them received ART to prevent perinatal transmission [32]. In May 2005, about 60 children infected with HIV had been identified.

There are only a few special organizations and institutions in Poland that offer HIV prevention and care. Those agencies are: the National AIDS Center, the Regional Sanitary-Epidemiological Stations, the Center for AIDS Diagnostics and Therapy, and the Sanitary-Epidemiological Council (an advisory body). NGOs play an important role in HIV prevention and give support to people living with HIV/AIDS throughout the country. Their financing comes from a variety of sources, including local and regional governments, private sponsors and pharmaceutical companies.

The Federation for Women and Family Planning carried out their project from March through May 2005 in the cities of Szczecin and Warsaw, interviewing eight individuals who are respected as experts in the field of HIV/AIDS.

South Africa

Epidemiological surveys carried out in South Africa give varying estimates of how many people have been infected with HIV [33]. UNAIDS estimates that about 5.3 million people, including 230,000 children younger than 15 years, were living with the virus by the end of 2003, with 21.5% of adults aged 15 to 49 infected [34]. In 2003, HIV prevalence among women surveyed at antenatal clinics in South Africa was 27.9% [35]. In one study done some years earlier in KwaZulu Natal, as many as 40% of abortion clients tested HIV-positive [36], but more HIV-positive women may be choosing to carry pregnancies to term now that ART is at least somewhat available.

A national program to prevent perinatal transmission of HIV (PPT) established 18 pilot sites, two in each province [37].² Through these programs, women are offered VCT during antenatal care; those who test positive then receive antiretroviral drugs at delivery for themselves and for the newborn infant. Three PPT demonstration sites in Durban, Langa and Johannesburg also offer women access to ongoing ART after they give birth [38].

In December 2003, the South African government completed its plans to provide universal access to ART to all South African citizens and permanent residents who meet specified criteria, which include CD4 counts less than 200 and residence near enough to an accredited ART service point to which they can report for periodic follow-up and monitoring. The plan mentions a number of entry points into the health-care system, including primary health-care clinics, VCT sites, PPT programs, clinics offering services related to reproductive health and sexually transmitted infections (STIs), tuberculosis clinics, inpatient hospital settings and prisons [39]. Although originally envisioned to offer ART to 53,000 patients in 2003 and 2004, by October 2004 less than 15,000 people were receiving treatment at public-health facilities due to delays in rolling out the program [40].

A coordination team made up of GAF staff, volunteers and women living with HIV from different organizations and support groups worked on the project design and identified the geographical areas where the project would take place. They decided to focus on three areas of KwaZulu Natal: one in the Pietermaritzburg region, one north of Durban and a township close to Durban. They collected data from 22–31 March 2005; preparations for the project began in January 2005 and finalization occurred in July 2005.

² The commonly-used terms PMCT or PMTCT — prevention of **mother**-to-child transmission of HIV — can carry unintended connotations of “blaming” the mother if a newborn infant is infected; with the term “parent-to-child transmission,” the same danger of implicit blame applies. We therefore advocate for use of the more neutral term “perinatal transmission,” which was used in the past.

4. DATA COLLECTION AND PRESENTATION

4.1. DATA-COLLECTION METHODS

The project description contained suggestions for different possible data-collection methods: interviews, facility visits and observation, mystery client visits to health facilities, document collection and review, and review of referral records.

Almost all project partners gathered most of their information using oral or written surveys comprising the sample questions provided by Ipas. FEIM, GAF and ICW adapted the questions slightly for their various categories of respondents. Four projects — GAF in South Africa, ICW in Lesotho and Swaziland, WOFAK in Kenya — also organized focus-group discussions with respondents.

All the partner organizations reviewed documentation related to HIV/AIDS policies, laws, regulations and programs within their countries, as well as a selection of IEC materials (including some they had produced themselves). ICW reviewed a number of human-rights documents with their respondents, including the *Barcelona Bill of Rights* [41], the *UNGASS Declaration of Commitment* [42], the *Abuja Declaration* [43] and the *Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)* [44].

The *Barcelona Bill of Rights* was formulated by representatives of international and national organizations gathered at the 2002 International Conference on AIDS in Barcelona, Spain. It delineates the human rights that must be respected and fulfilled for women affected by HIV/AIDS if the world is to achieve a gender-equitable response to the AIDS pandemic. The *UNGASS Declaration of Commitment* was adopted by the UN General Assembly at a special session on AIDS in June 2001. The *Abuja Declaration* was adopted by the Organization of African Unity in September 2001. Most of the other project partners provided their respondents with a copy of the *Barcelona Bill of Rights*, which is the document that most specifically addresses sexual and reproductive rights.

Argentina

Rather than use the sample questionnaire from the project description, FEIM prepared a survey using questions taken directly from the monitoring tool. These questions were adapted to be relevant for representatives of government agencies, NGOs, health-care providers and health-service clients (people living with HIV).

The clients represented three associations of HIV-positive people, including one organization specifically focused on women living with HIV/AIDS. Among the 24 respondents were also staff of the national and municipal AIDS programs, other state health programs, four hospitals and civil-society organizations focused on AIDS and broader issues. Twelve respondents were directors of health services or NGOs.

FEIM's project also incorporated a review of relevant materials produced by NGOs and official statistics and epidemiological information disseminated by the government.

Kenya

In Kenya, the project coordinator, who was located in Nairobi, reviewed the sample questionnaire provided by Ipas with seven WOFAK members who were asked to collect data: two women each in Kisumu and Mombasa and three women in Nairobi. They used the questionnaire without any adaptations. Respondents completed the questionnaire on their own but could ask the WOFAK members for clarification if they did not understand a question or terminology used in a question (for example post-exposure prophylaxis, also known as PEP).

In each city, 10 women who were WOFAK members but also affiliated with other CBOs, NGOs or parastatal organizations completed the questionnaire. In addition, six other women who participate in a network of HIV-positive people or in organizations that collaborate with WOFAK filled out the survey, as did representatives of two hospitals in Nairobi, three organizations that provide family-planning and reproductive-health services, an organization for HIV-positive people, and a program related to HIV/AIDS at the Ministry of Education. This resulted in a total of 43 survey respondents.

WOFAK further conducted three focus-group discussions, each involving 10 persons and lasting two or more hours. One discussion was with men living with HIV/AIDS, one with women widowed due to AIDS, and one with HIV-positive women younger than 30 years. The sample questions were used to inform the discussions but the topics were not limited to the issues the questions covered. For example, the main concern expressed by the men was the maternal mortality rate and number of children orphaned by AIDS. They concluded that it is evident that keeping mothers alive will also reduce the infant mortality rate. The HIV-positive widows' main concerns were related to property ownership and inheritance rights and protecting their daughters against HIV infection.

Lesotho and Swaziland

As mentioned in the Introduction, ICW incorporated the project into workshops that they had already planned to hold in Lesotho and Swaziland for women living with HIV. They adapted the sample benchmark questions for incorporation into a larger survey that was distributed to the women about one week before the five-day workshops. Most of the women submitted their questionnaires by the second or third day of the workshop. It is likely that some participants completed the survey together as several of the returned questionnaires had similar answers.

All 20 workshop participants in Swaziland completed the survey. All had been aware of their HIV status for periods ranging from four months to 15 years, and 11 were younger

than 30 years of age. All were involved in support groups or associations of people living with HIV/AIDS. The majority of these were mixed-sex groups; five participants belonged to women's support groups. About a third of the participants held formal positions within their organizations, such as chairperson, coordinator and secretary. One woman had founded her own support group.

In Lesotho, 14 of 25 workshop participants turned in questionnaires; 10 of the 25 participants arrived at short notice, so ICW was unable to contact them beforehand to distribute the questionnaires. Seven participants were younger than 30 years. They were all open about their HIV status and had been living with HIV for one to nine years. All of them belonged to mixed-sex support groups; two respondents had formed their own support groups. Nearly all of the respondents held formal positions within the groups, such as treasurer, secretary, chairperson and director.

Focus-group discussions further took place on the evenings of Day 3 (Swaziland) and Day 4 (Lesotho) of the workshops. As the workshops proved to be very intensive, participants were invited to attend the discussion on a voluntary basis, and pains were taken to ensure that they did not feel constrained to attend. Seven women took part in the focus group in Swaziland and 11 in Lesotho. Both unstructured discussions lasted from 1.5 to two hours. The facilitators tried to make sure an opportunity was given to talk about each of the main areas in the survey but they felt it was important to allow participants to focus on the areas of most concern to them. In Swaziland, the principal topic of discussion was violence against women, particularly sexual violence. In Lesotho, the main topics to emerge were reproductive rights, especially the right of women living with HIV to have children, and the function of support groups and other support networks. Other relevant parts of workshop sessions — for example, the section on sexual and reproductive rights — were documented and referred to in the project report.

Mexico

The project coordinator first interviewed two members of PECAC who also work at hospitals in Chetumal. Then these two staff members, the project coordinator and a fourth PECAC staffer carried out the other interviews.

A total of 27 persons participated in the interviews, which were based on the sample questions provided by Ipas. Twenty-four respondents represented five hospitals and clinics, other health facilities (such as the blood bank and Red Cross facilities) and government agencies such as a program for adolescents at risk, an institution focused on women and a human-rights body. They worked at 17 different institutions; those from the same institutions worked in different departments.

The sample questions were adapted slightly so that three women living with HIV could also be included among the respondents. The other people who participated were directors of institutions, chiefs of epidemiology, chiefs of HIV/AIDS programs, doctors, nurses, social workers and other types of employees. PECAC data collectors distributed copies of the *Barcelona Bill of Rights* and an Ipas brochure on EC to all the people interviewed.

Visits were further paid to six pharmacies, where staff were interviewed about the sale of EC.

PECAC collected samples of relevant information and education materials available at 12 sites. These included brochures and posters dealing with HIV/AIDS, family planning, contraceptive measures and human rights. They also collected civil and penal codes on abortion and state and federal regulations on adoption so that these could be reviewed for the study.

Poland

The Federation began its project in Poland by first reviewing all available materials on the issues under investigation, including the Federation's own reports and materials. These included research results, statistical and medical reports, legal documents, NGO organizational plans and status reports, books, manuals, booklets, leaflets, magazines, advertisements and ad campaign materials. In addition, recent data on the epidemic, HIV/AIDS fact sheets and other published materials were gathered from the Internet. The Federation found that, overall, information on women and HIV/AIDS was scarce.

Eight people were approached for interviews based on their expertise in the field. In a couple of cases, it proved quite difficult to arrange appointments, as the experts were extremely busy; however, once the interviews took place, the respondents were quite happy to participate in the study and interested in learning the results. Respondents included representatives of two medical facilities who were involved in PPT programs (one of whom is considered the national expert on women and AIDS) and a staff person of the National AIDS Center in Warsaw. The leaders or directors of five NGOs in Warsaw and Szczecin that focus on HIV/AIDS-related work and located were also interviewed. The interviews lasted an average of one hour.

The Federation's researcher further visited a number of facilities, including one hospital, two diagnostic centers and five NGOs in Warsaw.

South Africa

GAF chose to focus their project on five of the main benchmarks in the monitoring tool: 1) eradication of health care-based stigma and discrimination; 2) access to family-planning information that addresses contraception in relation HIV/AIDS; 3) access to

termination of pregnancy (TOP); 4) availability of high-quality VCT services; and 5) provision of Pap smears as part of gynecological care.

For GAF, the research process was as important as the research data obtained; their project was accordingly more time-consuming and complicated than the other projects. The process ensured that:

- Representatives of the women most affected by HIV/AIDS participated in data collection and analysis.
- There was a transfer of confidence and data-collection skills to study collaborators.
- The women being interviewed were properly briefed weeks prior to the interviews and focus groups so that they had sufficient time to decide whether to be part of the research.
- The final country report reflected the voices and the experiences of the whole team.

There were eight steps in the research process. The first step was to establish three research teams comprising:

- A team leader who had had significant and relevant research experience
- A GAF staff member or volunteer with no, limited or some prior research experience
- Two women living with HIV from either an activist or support-group background

The total number of researchers was 11, since one woman was ultimately unavailable to collect data due to work pressures.

The second step was identifying three study sites (one near Pietermaritzburg and two near Durban); GAF's point of entry was the local support groups for women living with HIV/AIDS. They then identified local clinics and area hospitals as secondary sources of information, together with HIV/AIDS-related NGOs.

In the third step, a member of the coordination team set up appointments with members of the support groups to brief them about the project and invite them to be part of a focus group. The informed consent process was presented and discussed. Participants were advised to consider their participation and to make decisions about this participation by the date of the data collection. These initial meetings took one to four hours to ensure that the group members fully understood the project and had the information they needed to make informed decisions about participating.

The fourth step involved a training workshop for the research teams, which was facilitated by a team leader from the Gender Studies Unit at the University of KwaZulu Natal, Thenjiwe Magwaza. This workshop covered: definitions of research from a knowledge-systems and a feminist perspective, research principles, data-collection and analysis techniques, an introduction to the MDGs and a review of international human-rights instruments. The workshop provided an opportunity to review, test and discuss the sample questionnaire, which was subsequently amended.

During the data-collection phase, each team member was responsible for writing up, on a daily basis, the information shared during the interviews and focus groups, as well as her experiences as a researcher. In step 6, the teams met for a one-day debriefing and initial data-analysis workshop, facilitated by Vicci Tallis, a team leader. After preparing an exhaustive list of the issues raised, they decided on the framework of their report. In the seventh step of the process — drafting the country project report — each team member was assigned to write specific "case studies" and stories. A woman living with HIV in Limpopo Province who works for an NGO also wrote about her own experiences and the experiences of people with whom she works. Her experiences echoed the stories heard in KwaZulu Natal. One team member assembled and edited the first draft, which was circulated so that each team member could make comments. Another team member reviewed the report before it was submitted to Ipas. The final step was the organization of a feedback session for all the women interviewed in July 2005. The findings were outlined and discussion took place about strategies to address the discrimination and oppression that women were experiencing.

Table 1: Data-collection methods used by the project partners.

Project partner	Type of data collection method				
	Questionnaire completed by respondents	Questionnaire-based interviews	Focus-group discussions	Document & literature review	Visits/observation
FEIM, Argentina		24 persons		Yes	6 hospitals 3 health-care centers 5 NGOs
Federation, Poland		8 persons		Yes	1 hospital 2 diagnostic sites 5 NGOs
GAF, South Africa		20 persons	5 groups		
ICW, Lesotho	14 persons		11 persons (1 group)	Yes	
ICW, Swaziland	20 persons		7 persons (1 group)	Yes	
PECAC, Mexico		27 persons		Yes	12 facilities 6 pharmacies
WOFAK, Kenya	43 persons		30 persons (3 groups)	Yes	

Table 2: Types of respondents approached by the project partners.

Project partner	Type of respondents (No.)				
	Women & men living with HIV/AIDS	NGO directors/staff*	Clinic & hospital staff	Other health facilities	Governmental program staff
FEIM, Argentina	6 persons (3 PHA groups)	8 persons (3 PHA groups & 5 NGOs)	7 persons (7 service facilities)		5 persons (2 national & 1 provincial AIDS program & 2 municipal programs)
Federation, Poland		5 persons (1 group of women living with HIV; 3 NGO representatives were HIV-positive)		2 persons (PPT programs)	1 person (national AIDS program)
GAF, South Africa	38 persons (37 women & 1 man)	4 persons	7 persons		
ICW, Lesotho	14 women				
ICW, Swaziland	20 women				
PECAC, Mexico	3 women		10 persons (3 hospitals, 1 clinic, 1 urban health center)	8 persons (2 in-state-level facilities, blood bank, medical association, laboratory) 6 pharmacy staff	6 persons (including programs on population, women, adolescents, human rights)
WOFAK, Kenya	36 persons	4 persons (3 NGOs, 1 PHA association)	2 persons (2 hospitals)		1 person (Ministry of Education)

*The persons identified as HIV-positive in the projects carried out by FEIM and the Federation also represented NGOs.

4.2. DATA PRESENTATION

Ipas did not tell the partner organizations how they should present their findings. Rather, they were asked to provide data related to each of the benchmarks they assessed, as well as answers to a series of logistical questions (Appendix 3). As a result, formats in which the reports were submitted varied considerably.

Four reports were delivered in English (by the Federation, GAF, ICW and WOFAK) and two in Spanish (by FEIM and PECAC). Each partner presented a narrative report summarizing their findings regarding each benchmark. PECAC also submitted detailed responses to the questionnaires given by their respondents, while WOFAK quantified responses in tables.

FEIM, GAF and ICW included direct citations from interviews and focus groups to illustrate key points. All the partners except GAF and ICW provided some background information on the HIV/AIDS situation in their country, while the Federation, FEIM and WOFAK also gave some information on the national response to the HIV/AIDS epidemic.

5. PROJECT FINDINGS

Ultimately, not all the project partners collected information on all 10 benchmarks specified in the project description. In a couple of countries, very little information was gathered specifically on stigma and discrimination, alternative parenting options such as assisted conception and adoption, and the availability of information and services related to abortion as an option for dealing with unwanted pregnancy. Three partner organizations commented, for example, that it was difficult to address abortion because legal termination of pregnancies is rare in their countries. Some partners added topics for assessment, such as gynecological care, including Pap smears, and implementation of the GIPA Principle (Greater Involvement of People Living with HIV/AIDS).

The issues about which information was collected can be grouped into six main categories:

- The availability of two specific measures to help women prevent HIV transmission: VCT outside the antenatal care setting and provision of PEP to survivors of sexual assault
- Fertility regulation, including access to contraceptive information related to the context of HIV infection, access to a range of contraceptives, availability of EC, and availability of safe abortion services
- Parenting options for persons living with HIV, including possibilities for assisted conception (such as sperm washing and in-vitro fertilization), PPT and legal adoption
- HIV/AIDS-related stigma and discrimination within the reproductive-health sector
- The use of human-rights documents as a framework for provision of HIV/AIDS and reproductive-health programs and services
- The involvement of women living with HIV/AIDS in formulating, implementing, monitoring and evaluating reproductive-health policies and programs

Key findings from each project are presented under each category; if a country is not listed in a particular category, it is because the topic was not addressed at all. General conclusions about the findings across countries are drawn in Section 7.

5.1. AVAILABILITY OF VCT AND PEP

The World Bank has noted that achievement of MDG 6 will depend partly on ensuring access to voluntary HIV counseling and testing (VCT) [11]. Ideally, women should be enabled to learn whether they are HIV-positive or not at a time of their choosing, not only when they are pregnant. Expansion of VCT to reach women outside the antenatal care setting is therefore of great importance, particularly since counseling before pregnancy can help HIV-positive women consider their options for safer pregnancy and

parenting and HIV-negative women can consider their options for protecting themselves against transmission.

Sexual violence against women is a pervasive problem worldwide; if a perpetrator of assault is HIV-positive, there is a definite chance of transmission, particularly if the victim is wounded during the attack. This has been recognized by some governments through policies that aim to ensure that survivors of rape are offered PEP if they report the crime soon enough to benefit from this form of antiretroviral treatment [45–46]. PEP availability appears to be restricted, however, even in countries that have had relevant policies in place for some years [47].

Argentina

The availability of VCT is very unequal throughout the country. Some provinces have multiple VCT sites, while others hardly have any. In the Buenos Aires area, Centers for Prevention, Counseling and Diagnosis of HIV/AIDS offer VCT outside hospitals; their counselors are HIV-positive people who are known to observe confidentiality. Despite the availability of these centers, it appears that many women only learn their diagnosis through antenatal testing. An increasing number of pregnant women are agreeing to be tested, although it is known that pre-test counseling is not always adequate. In 2003, 80% of pregnant women identified as HIV-positive learned their diagnosis during pregnancy.

Government norms dictate that PEP should be available in the same manner as EC, stating that emergency rooms should have PEP kits with a month's supply of prophylactic drugs. This requirement is not always fulfilled and, in practice, availability of PEP is restricted to a few facilities that provide it in cases of labor accidents or rape. There is no registration of the number of cases in which PEP has been provided.

Kenya

Three of the four NGO representatives and 32 of the 36 HIV-positive respondents said their organization provides VCT or referrals for VCT; it was unclear, however, whether some or most of the HIV-positive respondents were referring to WOFAK itself or to the other organizations for which they work.

Amnesty International has stated that overall access to PEP is lacking for rape survivors in Kenya [48]. The project coordinator stated that only the Nairobi Women's Hospital provides PEP, although this institution is attempting to help scale up services for survivors of violence in the provinces. Nevertheless, 15 HIV-positive respondents and two NGO representatives believed their organizations make PEP available, although 10 HIV-positive respondents did not know how many women have actually received PEP and four said that it has not yet been provided in any cases.

Lesotho

Almost all 14 respondents to the survey cited at least one provider of VCT outside the antenatal care setting, including hospitals, clinics, the Lesotho AIDS Programmes Coordinating Authority (LAPCA), the Seventh Day Adventist Church and NGOs such as CARE, Population Services International (PSI) and the Planned Parenthood Association.

The focus-group discussion revealed that there is a significant lack of women-centered or maternal health services in Lesotho, and even fewer rape crisis services. Only three of the 14 survey respondents said that PEP is available for survivors of rape or incest. None of the other respondents thought that PEP is available in Lesotho, despite reportedly endemic levels of rape and incest.

Mexico

PECAC determined that VCT is available in Chetumal at various sites, including health facilities and NGOs. The maternity hospital offers an HIV test to all pregnant women who give their informed consent.

Almost all respondents asserted that their institutions offer testing or referrals for testing; one of the three women living with HIV said she learned of her diagnosis during antenatal testing. It was interesting to note, however, that somewhat contradictory information about the availability of VCT was given. For example, the chief of epidemiology at one hospital said a lot of money is spent on VCT, with more than 150 tests done monthly: thus far, 19 seropositive women have been identified, some of whom were pregnant. Another staff member of this hospital confirmed that tests are done but said that there is no counseling or accompanying support provided. A staff member of an urban health center said that no women were identified as HIV-positive in 2004, while a colleague said they had referred two HIV-positive women to the General Hospital of Chetumal. What became clear to PECAC is that no statistics concerning testing and referrals for testing are registered.

Respondents also gave somewhat contradictory information about PEP. The director of one clinic said that two persons who had had occupational exposure to HIV had been able to access PEP, while two staff members of this clinic said that PEP is not available for anyone. The director of a hospital said that only pregnant women who have been raped are given ART. Other respondents said that PEP is offered at the Chetumal General Hospital, which was confirmed by a senior staff member there; however, this person later said in response to another question that no survivors of rape had received PEP, indicating that it is apparently reserved for occupational exposures. As is the case with VCT, it became apparent that no statistics are registered on how many people actually receive PEP in Chetumal.

Poland

VCT is only available at specialized hospitals and not at general public hospitals in Poland. Voluntary HIV counseling and anonymous tests are available free of charge at the Epidemiological Station – an easily accessible clinic – in every large city. Most women do not believe they are at risk of HIV infection, however, and therefore do not visit VCT sites.

Twelve reference hospitals offer ART in Poland. PEP is available without charge for people who may encounter a risk of HIV infection through their work activities, such as nurses, doctors, firemen and policemen/policewomen. In 2004, the 12 reference hospitals registered 354 cases in which they offered PEP, which included 223 work-related exposures and 131 outside-work cases including rape, piercing with suspicious needles, and attacks that involved piercing by drug users. However, it was unclear to the Federation how often rape survivors are told about the existence of PEP. The project coordinator received contradictory information about whether PEP is free of charge for cases of exposure outside the work setting. It appears that the people exposed in such circumstances must pay for PEP and go to a reference site to obtain it.

South Africa

South African research has estimated that persons raped by an HIV-positive perpetrator have a 30 to 40% chance of contracting HIV [49]. This high percentage might be related to factors such as the high prevalence of HIV generally in the South African population, the fact that a high percentage of rapes in the country involve multiple perpetrators, and the fact that violent rapes often result in genital injuries which facilitate transmission of HIV [50]. Recognizing the serious possibility of HIV transmission through sexual assault, the government adopted a policy authorizing PEP provision to rape survivors in 2002.

The respondents in the South Africa project did not discuss PEP because most of them were already HIV-positive. They did discuss domestic and sexual violence, however, because HIV-positive women are not safe from these forms of abuse. Women after woman told stories in the individual interviews and support groups of being in abusive intimate relations where they experienced regular beatings and forced sex. Women spoke of the lack of family support to address violence within their relationships. This was mirrored by how families deal with HIV infection: many women spoke of having little or no family support when they disclosed their HIV status.

The project revealed that HIV has also given rise to new forms of violence. Women in support groups and health-care workers reported that male partners are deliberately breaking condoms in order to demonstrate their power, because they are angry at being expected to use condoms and because they want to impregnate their partner. Another form of HIV-related violence occurs when husbands and partners send women to the clinics for ART and then take the drugs themselves. The men do this because they wish

to avoid the process of accessing these drugs, which includes counseling and a level of disclosure. Some women in one support group spoke of their husbands *“finding drugs and throwing them away.”*

Swaziland

In Swaziland, VCT is offered at all government hospitals, some health centers and clinics, and some NGOs such as the Red Cross, Family Life Association of Swaziland, PSI and the AIDS Information and Support Centre. However, reaching those sites often entails a significant journey for people living in isolated regions. Moreover, the focus-group respondents said that accessing the services may result in suspicion or unwanted disclosure for those women who must obtain their husband or parents' permission before making such a journey or visiting a health-service provider for any reason.

There are reportedly no special health-care units for survivors of rape or incest in Swaziland. The focus-group respondents remarked that marital rape is not acknowledged by law or custom, adding that many women, especially older women, who report incidents of sexual violence or rape are mocked.

Approximately half the respondents believed that PEP is available for survivors of rape or incest, and three of them mentioned hospitals where PEP is available. The other half did not believe it is available or were unaware of its existence. One woman believed that it can only be accessed in the capital city's hospital. Another believed that the process for obtaining PEP can be very long because a doctor's prescription is required.

During the focus-group discussion, one participant described how her daughter had been sexually abused, noting that a doctor was prepared to offer her PEP if she had undergone penetrative sex. The focus-group members nevertheless thought that PEP is generally not known among the public and that women reporting a case of rape or incest would not necessarily be recommended or offered PEP due to ignorance among service providers dealing with the incident — police, doctors, nurses, etc. — especially in rural areas.

5.2. FERTILITY REGULATION IN THE CONTEXT OF HIV/AIDS

Since the year 2000, an increasing number of agencies around the world have called for better collaboration between family-planning and AIDS programs because avoiding pregnancy can help reduce perinatal transmission rates [51–53]. In this context, it is important that women living with HIV be informed about contraceptive methods in relation to HIV/AIDS (such as possible interactions between hormonal contraceptives and drugs used to treat opportunistic infections); retain the right to make informed decisions about contraceptive use (that is, not be forced to use contraceptive methods that health-care providers can control, such as injectables); and be enabled to access

various options to regulate their fertility, including ways for dealing with failed contraception.

Argentina

Research by Human Rights Watch in late 2004 revealed that many women in Argentina face major barriers to accessing contraceptives, including male spouses who prevent them from obtaining and using contraception and health-care providers who provide them with faulty information about various methods [54]. In 2004, a study was carried out in Buenos Aires regarding guidelines and dissemination of information on contraception for people living with HIV/AIDS; unfortunately, this information does not appear to be well-known to staff of the Municipal Program on Sexual Health and Responsible Procreation. Informational materials on fertility regulation for HIV-positive people are scarce; some respondents knew of materials aimed at health professionals but not of materials for clients. Both governmental agency and NGO representatives considered this a new theme to be addressed.

There appear to be few links between care and support programs for HIV-positive people and reproductive-health programs. Although a few publications have stated that the two types of programs need to collaborate, this is not occurring. This disconnect is found at all levels, ranging from national programs to hospitals and clinics. One respondent commented: *"... in practice, no one has assumed responsibility for addressing contraception for people with HIV... contraceptive services don't figure into the picture of AIDS [although] in reality it concerns one person; sexuality is not differentiated in the sense of 'now I'm going in relation to reproduction' and 'now I'm going in relation to HIV.'"* The coordinator of a major reproductive-health program in Bahía Blanca commented that he had taken the initiative to collect AIDS-related materials but none of them addressed contraception. This was disturbing for FEIM, because they had produced and disseminated materials that address family planning and HIV/AIDS throughout Buenos Aires and Bahía Blanca.

Health professionals only advise people living with HIV/AIDS to use male condoms. One physician commented that such counseling is difficult because health-care providers know that people find it hard to use condoms consistently in contrast to, for example, an IUD which, after being placed, can then be forgotten. Some respondents said constant condom use is an especially difficult subject for serodiscordant couples. A woman living with HIV remarked that, although HIV-positive people intend to always use condoms, it is not always possible. However, they won't discuss this with health-care providers because they don't want to be judged and reprimanded.

A staff member of an AIDS program in Bahía Blanca noted that until a few years ago, some women living with HIV had tubal ligations; the program helped them obtain permission from the Hospital Bioethics Committee for this procedure. This trend

reversed with the introduction of ART. Some respondents said women should now be informed about the risks they run with pregnancy if they have high viral loads.

None of the persons interviewed in Argentina said that women receiving ART are required to use certain contraceptive methods. However, they noted that many health-care professionals, apart from physicians and gynecologists specialized in AIDS care, believe HIV-positive women should not be sexually active at all nor even think about having children.

The availability of EC in the public health sector depends entirely on the willingness of provinces and municipalities to spend part of their budgets on this contraceptive supply. The Buenos Aires municipal reproductive-health program has purchased EC supplies but respondents noted that not every health-care provider is willing to provide information about and prescribe the contraceptive. Women therefore need to know exactly which clinics are willing to provide EC, yet many women do not know about their right to obtain it. In Bahía Blanca, dedicated EC products are not available but some clinic staff will provide the Yuzpe regimen using regular contraceptive pills. Again, however, many women do not know they have a right to EC or how quickly after unprotected sex it must be taken. No statistics are available on how many women have been able to obtain EC in the greater Buenos Aires area.

The subject of abortion and postabortion care was not raised, presumably because it was only at the end of 2004 that provincial Ministers of Health agreed to formally provide postabortion care to all women, regardless of their HIV status. Access to abortion is highly restricted in Argentina, with legal services only being available in cases where pregnancy poses danger to a woman's health or life or when a mentally disabled woman becomes pregnant due to rape [54].

Kenya

Thirty-four of the 36 HIV-positive respondents and three of the four NGO respondents said their organization has information, education and communication (IEC) materials available on contraceptives. The project coordinator commented that the two family-planning associations participating in the survey provide both contraceptives and informational materials to women living with HIV. WOFAK itself makes available IEC materials on possible interactions between contraceptives and drugs used to treat opportunistic infections, antiretrovirals and alternative herbal therapies.

All of the women living with HIV and three NGO representatives said they had IEC materials that explain fertility regulation options for women living with HIV; the options discussed include male and female condoms and EC. It was unclear whether the materials address other means of preventing or dealing with unwanted pregnancies such as the pill, injectables, implants and abortion. The project coordinator believed

that respondents did not mention abortion because most people believe this medical procedure is totally illegal in Kenya (although it is technically permitted when a woman's life is endangered by pregnancy) [55]. However, she knew of at least one NGO in the country that is treating the complications of unsafe abortions and Ipas is familiar with numerous Kenyan providers of postabortion care.

Respondents in the focus groups indicated that women receiving ART are required to use contraceptives — the emphasis is on condom use because it will prevent infection with a different strain of HIV.

Lesotho

The only methods of avoiding unwanted pregnancies that most of the women in Lesotho spoke about in the questionnaires were male and female condoms, which were felt to be widely available (although female condoms are more expensive and less generally known about). Two respondents cited the ABC approach to prevention — which refers to abstinence, being faithful and condom use. One woman said she felt informed about all the options but didn't know if they would all be available to all women, including younger women and those living in rural or hard-to-reach places.

During the workshop sessions, the women indicated that they knew of female condoms but that these are infrequently used since awareness of them is generally low, they are not seen as being user-friendly, they cost more than male condoms, and they are generally inaccessible, especially in rural areas.

Most respondents were able to cite one or two places that would be able to provide informational materials (and condoms), including hospitals, clinics, health centers, LAPCA, the Lesotho Planned Parenthood Association (LPPA), support groups and pharmacies. Only one survey respondent answered that she didn't know where she could obtain materials, but it was unclear whether she was referring to all methods/options for avoiding unwanted pregnancies or just male and female condoms.

Of the 14 women who filled out the questionnaire, two had had occasion to access EC. One specified that she had needed a prescription, and the other had obtained it in neighboring South Africa. About a third of the respondents thought EC isn't available in Lesotho and almost half didn't know where to access it. Two women stated that they knew where they could go to access it, one of them naming LPPA and hospitals.

Asked whether they felt aware of issues around contraception in relation to HIV/AIDS, all the respondents replied that they did not. One woman said she had a general understanding of contraceptive choices available to all women, but that she had not come across issues pertaining to HIV-positive women in particular. The same respondent said that women living with HIV couldn't get prescriptions for contraception;

she later revealed that her ART program requires her to use a specific type of contraceptive (either an IUD or injectable hormonal contraceptive). One woman said that she had bought a book (via the Internet) to learn more about the issues; she maintained that this information is not available in Lesotho. Others believed that information might be available from LAPCA, LPPA, UNAIDS, CARE Lesotho and health-care centers, in support groups and by word of mouth (sharing information, stories or personal testimonies from other people living with HIV and AIDS).

Only four women who completed the survey were on ART, three of whom were not subject to any regulations on contraception. As mentioned above, one woman was required by her ART program to use a contraceptive that could be controlled by her health-care providers (an IUD or injectables).

An early workshop session revealed that no participants had heard of microbicides. Abortion, which is legal only to save a woman's life [56], was not mentioned in any of the discussions.

Mexico

Several respondents stated that they have information on family-planning methods available for their clients, including HIV-positive women, but there did not appear to be much available on contraception in relation to HIV/AIDS. One physician said that her hospital's guidelines on use of antiretroviral drugs contains some relevant information and that this information is conveyed to patients during counseling. Other respondents said that the topic has not really been addressed yet or did not answer the question about why they do not have such materials available.

None of the respondents said that health facilities require women who receive ART to use any particular contraceptive method. However, one physician said that staff try to persuade women to use some form of family planning, while three other physicians said it is important that they use barrier methods to prevent reinfection and pregnancy.

When asked whether their institutions or programs have information available about ways that women can avoid unwanted pregnancies, several respondents talked about condoms. Two state-level respondents said that leaflets on EC are available, but three other respondents said such information is lacking. Almost all respondents said EC is not available without a prescription, several adding that the method is not offered at all health facilities. Interviews with staff of six pharmacies revealed that they were unfamiliar with the term "emergency contraception"; when asked if they sell it without a physician's prescription, five did not know what it was or said they do not sell it without a prescription. When the interviewers mentioned brand names, four of the six said they do sell it without a prescription.

No statistics regarding how many women have been able to access EC are registered, but staff at two hospitals knew of two and three women, respectively, who had accessed EC at their institutions.

Four respondents specifically stated that information about legal abortion is unavailable and that it is known some women have clandestine abortions. One physician also emphasized that the main focus regarding women with HIV is to prevent pregnancy through contraception or to protect a pregnancy using ART; abortion is a topic that is taboo and avoided. Abortion is legally permitted in the state of Quintana Roo to save a woman's life, in cases of pregnancy due to rape and in cases of fetal malformation [57].

Poland

In Poland, scarcely any attention is given to contraception in the context of HIV/AIDS because so few women are tested for HIV. Contraceptives can be bought with a physician's prescription but they are fairly expensive and not reimbursed through health-insurance schemes. Indeed, there is considerable opposition to distribution of free contraceptives or state refunding of contraceptive costs. The female condom is unknown, sterilization is against the law and many other methods are too expensive for a large number of women. Male condoms are used primarily in extramarital relationships.

Most of the publications available in organizations serving people with HIV are those published by the National AIDS Center. These materials address HIV/AIDS and pregnancy, as well as methods of avoiding HIV infection; none were found to provide information about contraceptives for HIV-positive people. There are general informational booklets available about contraception that focus on male condoms, EC and the dangers of unsafe abortion.

Women receiving antiretroviral drugs that could be harmful to a fetus are given strong recommendations to use contraception while on such therapy. The most commonly recommended "method" is to practice abstinence; that is followed by a recommendation to use the male condom. Some physicians will prescribe hormonal contraceptive pills. Whenever a woman decides to get pregnant, she is asked to inform her doctor so that any necessary adjustments to her antiretroviral treatment can be made in order to avoid any danger to her or the fetus.

None of the institutions visited offer EC to anyone; it can only be given with a physician's prescription. One project in Warsaw advocated that every rape victim be offered EC by the police but encountered very strong protests.

Abortion is legal only in cases when a woman's health is severely endangered [58]; usually HIV infection or AIDS is not perceived as a reason to justify induced pregnancy

termination. Women who want an abortion usually must go to a private clinic, accompanied by the fear that they are doing something against the law. Several respondents mentioned illegal abortions among HIV-positive women they knew personally or by word of mouth.

South Africa

A 1997 study on women's experiences with contraceptives found that their knowledge of different methods was limited [59]. Access to available methods was often restricted by health workers, who either promoted one method over another or gave advice on which method to use. Another study in 2003 focusing on EC found that services were not standardized across provinces and across clinics — with the Western Cape having the best services and KwaZulu Natal the worst [60].

The project interviews highlighted HIV-positive women's lack of information about contraceptives in general, and contraceptive issues for women living with HIV in particular. Women reported that health-care workers are not forthcoming with information about contraceptives and focus heavily on use of the male condom for preventing pregnancy.

Most of the women had heard about female condoms, but few had seen one and even fewer had had the opportunity to use one. Access to female condoms was said to be extremely limited and in most cases nonexistent.

Information given to women was not consistent from clinic to clinic. For example, there was confusion as to whether injectable contraception lasts for two or three months. Community knowledge, based on years of using injectable contraceptives, was that it is given every three months; however, at some clinics women were told to come back after two months. Women interviewed were unclear about whether women living with HIV need to be injected more often than women who are HIV-negative and, if so, why.³

Some women who are aware of the issues and their rights spoke of not having easy access to contraceptives, especially EC. One woman spoke of her protracted and

³ WHO states that: "The limited data available... suggest that potential drug interactions between many ARVs... and hormonal contraceptives may alter safety and effectiveness of both the hormonal contraceptives and the ARVs. It is not known whether the contraceptive effectiveness of progestogen-only injectable contraceptives... would be compromised, as these methods provide higher blood hormone levels than other progestogen-only hormonal contraceptives, as well as than combined oral contraceptives... if a woman on ARV treatment decides to initiate or continue hormonal contraceptive use, the consistent use of condoms is recommended for preventing HIV transmission and may also compensate for any possible reduction in the effectiveness of the hormonal contraceptive." [61]

stressful experiences in accessing EC *“after lengthy enquiries.”*

South Africa’s Choice on Termination of Pregnancy Act, which emphasizes reproductive choice and human rights in its preamble, permits abortion within the first 12 weeks of pregnancy upon request and up to the 20th week to protect a woman’s life, physical and mental health, in cases of rape, incest or fetal abnormality, and on socioeconomic grounds. Abortion is permitted beyond the 20th week if the woman’s life and health are at risk or in case of severe fetal abnormality [62]. Nevertheless, health-care workers still exert a major influence on women regarding their reproductive choices, often by providing misinformation, withholding information or giving incomplete or poor explanations. Women reported going to a clinic to request an abortion and being sent from the clinic to a hospital with no explanation. As one woman stated, the attitudes of health-care workers make women go *“to the streets for an abortion.”*

Women spoke of being afraid to ask for a termination of pregnancy (TOP) at clinics and receiving poor-quality care. One of the worst cases of abuse reported to the project team was of a woman living with HIV who said she was given the fetus to take home after the procedure. The nurses told her that they had done that much for her; since it was her decision, she must deal with the fetus, because they would have nightmares if they had to.

The support groups felt that most women do not know their rights and therefore agree to various instructions, bargaining with and accepting advice from health-care workers out of desperation. One group stated: *“TOP is not taken seriously. Nurses say we have too many rights and options.”* One woman told of a nurse who initiated a TOP as an *“instruction, not an option.”* TOP was also linked to forced sterilization, with women being told they would be given a termination only on the condition that they agreed to be sterilized. The issue of forced sterilization was reportedly much worse in the rural areas.

“I did try to get information when I was pregnant and I tried to abort and the doctor said that I must be aware that I can die because there might be a lot of bleeding. The support group really helped me a lot.”

“If we do access the services we are treated poorly — no respect, health-care workers are judgmental and often cruel: this adds to the emotional trauma of having a termination of pregnancy.”

“I opted for an abortion which was performed and I was dismissed and was told to go to home and return whenever I feel pains from this. When the pain finally came I could not even walk to the taxi rank. Other women had to assist me and that was a very embarrassing experience.”

SWAZI HATI

In general, the women in Swaziland were aware of methods for avoiding pregnancy, particularly male and female condoms. According to them, information and materials on preventing unwanted pregnancy are mostly available only in English and not in the local Siswate language. They said that materials are available through health-service providers, hospitals and clinics, VCT centers, HIV/AIDS information centers, UNAIDS, some NGOs, and pharmacies (to some extent). One respondent answered that materials on the different options are available at border posts and in public toilets. Microbicide research was discussed during the workshop, although all but one of the participants were unfamiliar with it.

During the workshop, the women commented that not all contraceptive options are easily and equally accessible by all women, particularly young women, women living in rural areas, women living with disabilities and widows. They suggested that financial stability is a prerequisite for being able to access options for preventing or avoiding pregnancy. The focus-group discussants felt that there are no sexual- and reproductive-health services for women living with disabilities and that, due to customary practices related to the death of a spouse, widows also find it hard to access all kinds of health care.

Most of the women felt uninformed about contraceptives in relation to dual protection, use of EC, breakthrough bleeding or spotting and, particularly, possible interactions between hormonal contraceptives and drugs used to treat HIV and opportunistic infections. Only one woman said that she felt informed about all of these issues, and only three answered that they knew where to go to find out more.

Two women said that most of their information and knowledge about contraception had come from the Internet (to which the majority of respondents had no regular access). Other information sources mentioned included workshops, health programs, support groups, counselors, clinics, national-level councils and the Ministry of Health. One woman reported that she tried to get information about contraception from her clinic; she was told that it was the same for HIV-positive and -negative women and that being HIV-positive made no difference. The respondents stated in the survey that it would be even harder for women living in rural areas to access information on contraception in relation to HIV/AIDS. None of the nine workshop participants who were taking ART reported that these programs require them to use certain contraceptives.

The questionnaire asked whether the women had ever needed to access EC and whether they knew where to obtain it if they ever needed to in the future. Ten of the 25 respondents answered that they had never required EC and wouldn't know how or where to access it. One woman reported that she had needed it but had not known how to access it, adding that she still did not know to this day. Another three had successfully accessed EC; they and others believed that they would be able to obtain it if necessary.

They mentioned pharmacies and the Family Life Association of Swaziland as places where EC is available.

Abortion is legal in Swaziland only when a woman's life is in danger; it is not granted on condition of HIV infection alone [63]. However, it is common for Swazi women to travel to neighboring South Africa to obtain abortions. The focus-group discussants said that there is generally a lot of pressure to carry even unwanted pregnancies to term and to put babies up for adoption rather than having an abortion. One woman reported having had an abortion when she was six months' pregnant because it had taken her that long to convince doctors that her health would be jeopardized by carrying and delivering the child full term. She was eventually referred to the Deputy Director of the Ministry of Health to obtain approval. The women expressed concern about reports of abandoned babies and infanticide when mothers were unable to cope with infants. Of further concern was the fact that there are no emergency abortion services available for women in remote areas, which leaves them very vulnerable.

5.3. PARENTING OPTIONS FOR HIV-POSITIVE WOMEN

In recent years, considerable attention has been paid to childbearing by women living with HIV/AIDS. The focus has been mainly twofold: supporting women's right to bear children by combating forced or coerced sterilization and abortion, and preventing perinatal transmission of HIV. Very little attention has been given to other issues related to parenting, such as the availability of assisted conception methods and legal adoption by HIV-positive people [64].

Argentina

NGO representatives in Argentina commented that HIV-positive couples considering pregnancy find it difficult to access any information about safe pregnancy. Respondents noted that there are very limited possibilities for serodiscordant couples to use assisted conception methods.

Kenya

None of the NGO representatives in Kenya said their organizations address legal adoption as a parenting option for HIV-positive persons. Reasons given for why the option is not addressed ranged from "*people are already taking care of orphaned children*" to "*not allowed by the government.*" Eleven HIV-positive respondents said their organizations do address adoption as an option, however, and 11 said they knew of HIV-positive people who had legally adopted children.

Lesotho

The workshop participants in Lesotho said that PPT programs are a major concern because women's needs are not properly addressed: the principal focus is on prevention rather than counseling, treatment and care for the HIV-positive mother. As one woman stated: *"They give assistance in the process of giving birth but no assistance in the process of planning, conception, checking that the woman is healthy enough and giving advice on what to do if your husband is negative."*

The workshop participants reported finding it almost impossible to access information about safe pregnancy and childbirth, advice on the optimal health conditions for conception, childbirth and early stages of motherhood, or guidance on how to maintain their health during these periods: *"I want to know exactly how secure I am — how safe am I as a positive woman?"* One participant said that she had ended up getting information from Positively Women, an organization from the United Kingdom, but that this information was too general and not locally relevant. The woman said that there was only one gynecologist working in Lesotho, and she wasn't convinced about her reliability.

Three of the 14 survey respondents reported that either they had legally adopted children themselves or knew of people living with HIV who had done so, but they did not supply any detailed information about this.

Mexico

None of the respondents in Mexico indicated that their institutions or programs had considered the issue of legal adoption by HIV-positive persons, stating that this was outside their scope of work. A few health professionals commented that it should be considered since HIV-positive people have a lot of love to give and should enjoy this right. The head of one clinic said that many factors would have to be taken into account in order to ensure that no HIV transmission occurs. The representative of a human-rights agency said that HIV infection should be treated like other chronic conditions, such as diabetes, so that it does not disqualify a person as an adoptive parent.

Although the civil code in the state of Quintana Roo does not mention HIV infection as a disqualifying condition for adoption, the regulations of the federal agency in charge of adoptions do not allow unmarried people, gay persons or anyone with a terminal disease to adopt; these regulations still designate HIV/AIDS as a terminal disease.

None of the respondents knew of HIV-positive people who had adopted in Mexico. Two of the three women living with HIV expressed interest in knowing whether legal adoption could be an option for them.

Poland

The law in Poland allows HIV-positive parents to adopt children and one NGO (included among respondents in this project) mediates in such cases. Issues of fostering and adopting children by HIV-positive people are included in some advocacy materials and NGOs take action to enable such adoptions. However, while the study revealed HIV-positive parents can certainly adopt an HIV-positive child, it did not become clear whether they can adopt an HIV-negative child.

Often adoption by HIV-positive adults is the only chance for a child living with HIV to have a family in Poland; however, it appears that more HIV-negative couples are now willing to take an HIV-positive child, although some of these couples are from other countries such as Germany and Italy.

Swaziland

The survey asked whether women felt informed about methods of assisted conception. Not a single respondent said she felt informed about any such methods. The questionnaire also inquired whether any women had themselves legally adopted a child or knew of anyone living with HIV who had done so. Two answered yes to that question, but without giving any details.

5.4. HIV/AIDS-RELATED STIGMA AND DISCRIMINATION

The persistence of HIV/AIDS-related stigmatization over the course of the pandemic has led to increasing efforts to examine how stigma affects prevention and treatment efforts and how it might be tackled [65–67]. As some approaches to combating stigma are showing success [68], we were interested in determining whether stigma and discrimination are still recognized as problems.

Argentina

The project team in Argentina did not focus on stigma and discrimination in their data collection but did confirm that it exists. One comment they gleaned from a program was illustrative: *“The issue of HIV-related work is pretty controversial in the hospitals... the services that proved to be most reactionary regarding condom distribution were those dedicated to mental health and gynecology. One hospital suggested having special hours for HIV-positive people so that they could carry out disinfection procedures afterwards.”*

Lesotho

All but three of the 14 respondents to the survey said they had experienced stigma and discrimination in the health-care setting. During the workshop proper, seven

participants mentioned negative experiences that included: having their status revealed by doctors and nurses without their consent; feeling stigmatized by other patients; being denied attention and proper communication during the doctor's consultation; a health worker being reluctant to give an injection; and a health worker failing to offer counseling or provide enough support. One woman told her experience of being wrongly treated and then discharged with severe complications which led her into a coma.

Mexico

Most of the persons interviewed did not know of any HIV-related cases of discrimination that had been officially reported to municipal or state authorities. Representatives of two hospitals said they knew of at least four and six cases, respectively, that had been reported and handled within their institutions. It was interesting to note that, at the hospital where a gynecologist reported that six cases were handled internally, the hospital director did not know of any such cases. Other respondents said they knew of discrimination cases but that these were usually not reported. One HIV-positive woman said she would not know where to submit a report; another said she knew of a woman who had suffered discrimination but who did not report it because she feared nothing would be done.

Asked what kinds of discrimination they had encountered or heard of, respondents mentioned refusals to examine or treat women, refusals to bring women food or clean their rooms in the hospital, and breaches of confidentiality. Such incidents were known to have occurred in the labor, postpartum, surgical and pediatrics wards, gynecology services, antenatal care, the emergency room and waiting rooms.

Poland

The interviews and literature research revealed that many HIV-positive women travel to larger cities for health care because the quality of care differs greatly between large city and local facilities. Respondents knew of cases in which women were refused help at hospitals and clinics; such incidents apparently occur more frequently outside large cities, though not always. They indicated that the special health-care institutions offering services related to contagious diseases and virology — such as several of the 12 reference sites that are responsible for administration of ART — are the only ones that guarantee stigma-free health services to people living with HIV/AIDS. In other cases, how care is offered depends on the attending doctor's attitude; unfortunately, many medical staff are still afraid because they have received insufficient education about the low occupational risks of HIV infection.

Respondents mentioned some difficulties encountered by HIV-positive persons during visits to dentists, but the extent of such problems was hard to estimate. No data was available concerning discrimination related to HIV/AIDS during postpartum or abortion-

related care. Most cases of discrimination appear to be related to surgery and gynecology, which led interviewed women to say that it is very important for an HIV-positive woman to have her own gynecologist who knows about infection and is not “*repulsed*” by the fact that she is seropositive.

Respondents said that a couple of times each year an intervention is needed when a hospital will not allow a pregnant woman who is known to be HIV-positive to deliver. The hospitals argue that they are not ready for such complicated cases, but the respondents believe that such refusals are due to fears of HIV infection and a lack of education among medical staff. In such cases, the women are usually admitted to a different hospital, as there is at least one hospital per region that is fully prepared to attend deliveries by seropositive women.

South Africa

The interviews and focus-group discussions with HIV-positive women indicated that their rights are regularly violated at health facilities in South Africa. The behavior of health-care workers toward clients is undermining, rude and dismissive. One woman from a support group said: *“If you are very sick, they shout at you and say that you are pretending. They tell you that you are not the only patient who is sick in the clinic, ‘so keep quiet and stop making noise.’”* Another woman who went for treatment of an opportunistic infection reported verbal abuse by a health-care worker who greeted her with the words *“How are you feeling today? You look like a granny.”*

Such stigmatizing and humiliating treatment was mentioned specifically in relation to STIs and Pap smears:

- *“Nurses make jokes and laugh at you.”*
- *“HIV-positive women are treated badly and given wrong information.”*
- *“...the nurses have no empathy and they shout at you when you eventually go for treatment.”*
- *“You do not get comfortable when you are having a Pap smear. The nurse performed a Pap smear on me in front of another sister, after me telling the sister that I don’t want the other sister to stay.”*
- *“Pap smears are performed on a woman without any information given about how it’s done. One nurse insisted on watching while the Pap smear was done to a woman and as the woman left the nurse made a joke out of it.”*
- *“They told us about Pap smears but when we came to collect our results they said that our results are missing and treated us without any respect.”*

Nurses who were interviewed blamed the women, noting that they are not finishing treatment and are not bringing in their partners for STI treatment. One nurse said: *“We cannot educate them because they are illiterate.”* This shows little empathy and understanding of the realities of women’s lives. Some women decide not to go to such

clinics because of the services received; one interviewed woman stated: *“Often they treat you very badly, in such a way that many people have stopped going to the clinic. Many people are dying through depression, stress and stigmatization.”*

Primary health clinics are supposed to open at 7:00 a.m., but people start arriving at 5:00 a.m. to ensure that they will be seen. The women in one area reported that one clinic never opens on time, sometimes not beginning to see patients until as late as 10:00 a.m.

A project team observed that the nurses at one clinic thought they were clients and therefore did not help them; it was only when the clinic staff learned the team members were doing a study that they were willing to speak with them. This clinic only sees 20 people per day for counseling on wellness and it was reported that they would not attend clients they did not know personally. It was further found that they did not have the necessary drugs on hand, did not offer PPT or pregnancy termination services, and only offered VCT and STI treatment.

There were many other examples from the interviewed women of not being attended at clinics. In their experience, being known by a health-care worker — through a support group, personal relationship or friendship or as a regular clinic patient — seems to be a prerequisite for treatment.

The HIV-positive women who were interviewed and who participated in the support-group discussions mentioned various instances where confidentiality was breached by health-care providers. Examples included: organizing wellness clinics for HIV-positive people in such a manner that others will see them attending and then know their status; informing potential in-laws about a woman’s HIV status before marriage; and asking support-group members in public about their attendance at support-group sessions. When one project team visited a health facility, a nurse there disclosed the name and HIV status of a support-group member, adding that the woman had become pregnant because her partner had pierced the condom and it had leaked. The team later met this woman in a support group and was able to identify her by her name and story.

The general feeling of the women living with HIV who were interviewed about clinic-based support groups was that the nurses’ attitudes were discriminatory and judgmental and that members were given little information and support. They said that attendance often meant discomfort, embarrassment and even trauma; in their view, the only benefit of attending clinic support groups was that members were more likely to get treatment.

“If people don’t pay regular visits to their support group, the health-care workers don’t have passion about their job and don’t care why the person was absent on that particular day. Instead they [the health -care worker] will call them names and it is even worse if that person is newly diagnosed. When the person cries, they will laugh and say that there is no space for crying people in the support group.”

— members of a support-group discussion

Although stories about discrimination predominated, two project team members each remembered recently visiting a clinic that did provide good services:

- *“The first thing that I noticed at this clinic was that the health workers are very nice to the clients. They give the clients good education about HIV and AIDS. The first day I went there I was with my sister who was pregnant. The nurses had smiles on their faces. They have specific services, e.g. counseling. Their counseling is very good. They also advise patients to go and do a Pap smear when needed and they teach them why they do that.”*
- *“The staff seem to be experienced at doing their work and they teach women about reproductive-health services. The nurses give advice to women about avoiding unwanted pregnancies, using condoms and prevention of HIV. Women living with HIV are informed about their options for parenting children. They have access to family-planning information that addresses contraception in relation to HIV and AIDS.”*

Swaziland

Over half of the survey respondents reported having experienced stigma and discrimination in the health-care setting on account of their HIV-positive status. Several respondents felt that this was a major issue regarding their rights to treatment and health care, including sexual- and reproductive-health care.

During the workshop, also, the issue of stigma and discrimination in the health-care setting came up on several occasions and was described in more detail. Incidents described ranged from disclosure of HIV status without consent to ridicule by health workers to refusal of treatment. One woman's HIV status was revealed to her cousin whom the health worker met by chance in the street; another woman who went for STI treatment reported how the health worker herded all those who had come for treatment in front of all the other clinic clients (*“STIs this way”*).

Judgmental attitudes among health workers and counselors were reported to be common, resulting in the feeling that counselors should all be HIV-positive themselves in order to avoid disrespectful attitudes: *“Counselors must know that HIV-positive women are just like any other women.”* Poor quality of service in health centers or no service at all were also reportedly common occurrences. One workshop participant was

told: *“Why have you come here? You are not sick. It’s part of what you are”*. Another woman said the health-center staff told her she couldn’t have children.

5.5. HUMAN RIGHTS AS A FRAMEWORK FOR PROVISION OF PROGRAMS AND SERVICES

A basic premise underlying the monitoring tool is that awareness of sexual and reproductive rights is essential for achieving the MDGs and for providing women living with HIV/AIDS with comprehensive health care. International human-rights conventions have established that all people have a right to health and health care. All countries that are members of the United Nations have endorsed at least one human-rights treaty that refers to the right to health; therefore, all UN member States are obliged to respect, protect and fulfill this right.

For example, to realize the right to health care, women should be able to discuss treatment with their health-care providers and be enabled to decide what kind of treatment to receive after being fully informed about the benefits and drawbacks of various options. With the advent of ART, projects are being carried out on “treatment literacy” in various countries, wherein patients are educated about antiretroviral drugs — the types of drugs available; when, how and why they are administered; possible side-effects; drug resistance; and so on. It is very often associations of people living with HIV who carry out such educational efforts, with support from UN agencies such as UNAIDS and WHO [69].

The right to health care is also being referenced in relation to the MDGs. Numerous UN, governmental, intergovernmental and nongovernmental agencies have issued background documents about how to achieve the MDGs in preparation for a World Summit to be held in September 2005. A recurring theme in many of their documents is that the MDGs will not be achieved unless all people are enabled to receive services related to their sexual and reproductive health. Some sample statements that express this view are:

- “The EU [European Union] further recognizes that the MDGs cannot be attained without progress in achieving the Cairo goal of universal sexual and reproductive health and rights... The empowerment of women and recognition of their sexual and reproductive rights is a necessary step in that context” [12].
- “Political leaders must recognize the critical importance of women’s health and empowerment, and of health systems to achieving the Millennium Development Goals (MDGs), and countries must endorse the ICPD (International Conference on Population and Development) target of universal access to reproductive health by 2015 as an additional target to MDG 5. These commitments are not optional. Women have a human right to health and to access to health care” [14].

- “There is an urgent need to involve women and men in addressing social norms that increase vulnerability of women... and provide full access to HIV information and services, including sexual and reproductive health services” [70].

The right to health has further been established in the constitutions or laws of countries around the world. It follows that people affected by HIV/AIDS and health-care providers need to be aware of the right to health and the obligation to provide care and treatment that it imposes on health systems. They also need to know that violations of this human right can be reported so that people who are denied proper care can seek fulfillment of their rights through national and international legal systems. Women affected by HIV/AIDS and health-care professionals should accordingly be familiar with international and national documents that explain sexual and reproductive rights, such as the *Barcelona Bill of Rights* and the *International Guidelines on HIV/AIDS and Human Rights* issued by the Office of the UN High Commissioner for Human Rights and UNAIDS [71].

Argentina

While some respondents had heard of the *Barcelona Bill of Rights*, none of them were really familiar with its contents. A few other documents recently published in Argentina on PPT and sexuality counseling mention that HIV-positive people have rights, but both governmental and NGO respondents stated that respect for those rights varies a great deal, both between and within services throughout the country, depending on the characteristics of the staff on duty. The respondents stressed that rights are not guaranteed simply by publishing and disseminating relevant documents but that training of health-service providers is necessary.

Kenya

WOFAK members appear to have at least some awareness about human rights and health: 22 of the 36 women living with HIV said they were familiar with the *Barcelona Bill of Rights*, nine of whom had copies of the document. On the other hand, none of the NGO representatives had heard of this document, although they all expressed an interest in receiving a copy. Only seven women living with HIV and one NGO representative were familiar with the UN international guidelines on human rights and HIV/AIDS; only three had a copy available to show clients.

Asked whether their organizations promote other human-rights documents, 19 of the 36 HIV-positive and two of the four NGO respondents said they did. These include brochures, books and videos. Six WOFAK members noted that distribution of free condoms provides them with an opportunity to promote sexual rights and distribute such informational materials.

Members of the focus-group discussion with widows remarked that they wanted law reforms that would create a supportive environment for women living with HIV to claim

their rights. The younger HIV-positive focus-group members stated that they are denied sexual and reproductive rights and commented that, because other people want them to abstain from sex, they are denied access to information and services. They were concerned that their rights to have protected sex and to choose with whom and where they want to have sex are not addressed. The young women further called for mentorship programs and capacity-building because they feel that their voices are even superseded by those of older HIV-positive women.

Lesotho

A survey question that asked respondents to identify which issues are of particular importance to women living with HIV/AIDS in Lesotho elicited 13 answers, seven of which specifically mentioned rights or empowerment.

Only two respondents were familiar with any of the international human-rights documents such as the *Barcelona Bill of Rights*, the UN international guidelines or CEDAW. One woman reported familiarity with the preamble to the *Universal Declaration of Human Rights*; three participants mentioned that they were aware of organizations with a rights-based mission in Lesotho but that these were neither specific to sexual and reproductive rights nor to women living with HIV/AIDS. The organizations they mentioned were Women in Law in Southern Africa (WLSA) and FIDA, an association of women lawyers.

One other respondent said she knew of a national policy promoting women's sexual and reproductive rights which is on display on the noticeboard at her workplace. The majority of respondents were not aware of conventions or guidelines being posted in health-care centers or family-planning clinics, although some mentioned that they are posted in the offices of organizations that advocate for gender equality.

The questionnaire asked whether the women had used any of these documents — or others such as the WHO treatment guide — in their own advocacy or activism work around women's rights, or whether their support groups used them to promote women's rights. Nearly all the respondents answered “no” to both questions. One woman mentioned that her support group used the *Universal Declaration of Human Rights* to support rights-based activism and advocacy, and three answered “yes” but without giving any details of which documents or how they were used.

Mexico

Only five respondents were familiar with the *Barcelona Bill of Rights*, four of whom said it could be given to their clients. The other respondents were interested in it and said they would consider making the copy they received available to clients. The representative of a local human-rights agency said it would henceforth be included in training courses and disseminated as a brochure or leaflet.

Asked about the guidelines on human rights and HIV/AIDS issued by UNAIDS and the UN High Commissioner for Human Rights, several respondents said they were familiar with the guidelines and had them available for the general public. However, it appeared that some respondents thought the question referred to human-rights documents in general. The three interviewed women living with HIV said they had heard about rights, for example, through talks but it was not clear to them exactly what those rights are and they had not received any written information about them.

When PECAC inquired whether their institutions or programs had other materials on sexual and reproductive rights, several respondents spoke about brochures and leaflets — many of which came from PECAC itself — on topics such as condoms, safer sex and ART. One physician also said that they ask people living with HIV to sign letters of commitment and support for ART but that the patients unfortunately do not always comply with their promises concerning treatment.

As PECAC was concluding its project, it came to their attention that one of the women living with HIV whom they had interviewed was going to officially file the first locally documented case of stigma and discrimination related to HIV with the Human Rights Commission in Chetumal. The woman had endured harassment from a gynecologist at a hospital for “*daring*” to get pregnant.

Poland

Most of the documents available at NGO or health facilities in Poland are publications financed by the National AIDS Center. These include a series of books about HIV/AIDS and legal issues, one of which addresses “international protection of human rights and HIV/AIDS.” This publication was the only one found during the project that discusses international legal questions; the literature review did discover a few articles on the rights of people affected by HIV/AIDS, but these did not include any information specifically for women.

The NGO activists appeared to be familiar with the *Barcelona Bill of Rights*, although they did not have copies of it or other human-rights guidelines available. They did not want a copy of the Barcelona document in English but said they would be willing to make it available to their clients in a Polish translation. However, none of the organizations had the resources to prepare this kind of information themselves and they questioned whether such documents would be useful for clients or service providers in everyday life.

South Africa

Few of the interviewed women living with HIV were aware of their rights, but one woman said she had tried to address a negative experience at a health facility by reporting the nurse in question to the nursing supervisor. She said that the complaint went no further,

given that the matron supports nurses. One of the major difficulties is that few women feel able to challenge health workers, since they occupy a position of power and there is always fear of the consequences for their future access to health care at that clinic. In addition, sustaining participation in a complaints process is often time-consuming, stressful and costly in terms of transport, time, and so on.

The project revealed that health-care providers may not be interested in having outspoken and educated patients. The women interviewed in South Africa believed that nurses are not well educated about HIV and AIDS and have had insufficient training and experience. One example was given during a support-group discussion of a woman living with HIV who asked the health-care worker for Bactrim® for prophylaxis purposes. The health-care provider responded very angrily, asking who had told her about the drug and inquiring why she had bothered to come to the clinic if she knew everything anyway. It was reported that nurses tell HIV-positive people that they give Bactrim® only to those with tuberculosis, not for prophylaxis.

One nurse admitted that she did not know much about treatment and other needs of women living with HIV. She noted that the clinic gets little information and skills-building training on these issues.

One focus group concluded that complaints would only be taken seriously if:

- Women know their rights.
- Women confront abuse and are able to identify access points where complaints will be addressed.
- Women are supported to follow through in registering and pursuing a complaint.

Swaziland

The survey question designed to elicit information on which issues are important to women living with HIV in the Swazi workshop produced a list of 40 items, 15 of which specifically mentioned decisionmaking and/or rights. Several of the other issues named were also related to rights, such as *“self-empowerment — being able to say NO.”* Three respondents said that they were aware of human-rights documents such as the *Barcelona Bill of Rights* and CEDAW. Another woman indicated that she was aware her government had signed on to CEDAW, but that she hadn't seen any evidence of implementation. None of the other respondents knew of the documents or guidelines — one despite having actively sought out such information at her health-service provider. Two women reported that their groups or organizations do promote reproductive rights for women living with HIV/AIDS, one of them through the publication of booklets. Another woman reported that her support group doesn't carry out this kind of work because there is only one woman in the group: *“All the others have passed away so the men are not interested.”* None of the respondents had used any of these policy instruments in their work around HIV/AIDS.

5.6. INVOLVEMENT OF HIV-POSITIVE WOMEN IN REPRODUCTIVE-HEALTH POLICIES AND PROGRAMS

The GIPA Principle was adopted by UNAIDS and other UN and nongovernmental agencies because they recognized that measures to tackle HIV/AIDS will not succeed unless the people most directly affected by the pandemic are involved in all aspects of programs. This was reiterated in June 2005 at the high-level UN General Assembly session to review progress in combating HIV/AIDS. A background paper for that meeting stated it is essential to *“ensure greater involvement by people living with HIV/AIDS and women in policy and decision-making processes and in implementation and monitoring of programmes”* [70].

Gender-based analyses of efforts to improve sexual and reproductive health have further asserted that women must be enabled to participate in policymaking and other decisionmaking if any success is to be achieved [13]. It follows that women affected by and living with HIV/AIDS must therefore be involved in decisionmaking regarding reproductive-health policies and programs.

Argentina

Formal mechanisms exist within governmental agencies and programs to involve associations of women living with HIV/AIDS in policy and program formulation and implementation. For example, in 2000–2001, the committee tasked with formulating guidelines on preventing perinatal transmission included a local ICW representative and a member of the Women’s Health Network of Argentina. The respondents to the survey had differing opinions regarding the effectiveness of these mechanisms, however.

National and municipal government representatives remarked that HIV-positive women’s groups receive funding to engage in policy and program implementation. Mention was also made of the fact that HIV-positive persons participate in the Country Coordinating Mechanism (CCM) of the Global Fund Against AIDS, Tuberculosis and Malaria (Global Fund). NGO representatives did not value the Global Fund as much as governmental respondents; none of the respondents said that HIV-positive women are currently involved in policy and program formulation and design.

“I was a member of the CCM for the Global Fund project for two years and I learned that...one must be well prepared regarding why one has a seat there, because not only does the system absorb you so that you end up supporting and endorsing things that are not related to the fundamental objectives of people living with HIV nor that represent what we want. And you pay for this with your physical state, by being criticized, by not knowing things. We left the CCM...We think our best strategy is to begin training the leaders of the network so that they can take such positions later when they are better prepared with more skills.”

– HIV-positive respondent in Argentina

At the service-delivery level, the health-care providers said they themselves should be doing community outreach work instead of only clinic-based work since this would give them a better idea of their clients' HIV-related needs. They and the HIV-positive respondents nevertheless acknowledged that trained people living with HIV may be better counselors than health professionals.

The health-care providers — especially those trained after the AIDS epidemic arose — expressed appreciation for the work of HIV-positive persons in prevention, support and education activities. As one physician said: *"In this ward they spontaneously organized a workshop, which enabled us to incorporate 600 patients in the program on responsible procreation which distributes the pill and condoms."* It was noteworthy that they spoke about involvement of HIV-positive people mostly in terms of implementing programs. One program head admitted that there could be difficulties in forming multidisciplinary teams that include HIV-positive members for policymaking purposes because *"it is very difficult and time-consuming to really find points in common for people with different viewpoints."* This respondent nevertheless added that it was a goal worth pursuing.

Kenya

In Kenya, at least five of the organizations represented among the HIV-positive respondents are supposed to be involved in national policy formulation; 31 of the 36 HIV-positive women said their organizations were indeed involved in policies and programs. Ten respondents specified that their organizations provide services such as group therapy or stigma-reduction activities. Only eight respondents said their organizational representatives were involved in decisionmaking. None of the NGO representatives said that their organizations required the involvement of people living with HIV/AIDS in formulating policies and programs.

Lesotho

The workshop participants in Lesotho noted that often they are the only representatives of people living with HIV and AIDS at a meeting or public gathering organized by other organizations. They highlighted the fact that they are often called at very short notice, without time to gather the opinions or views of others. Representation can mean as little as being present at a meeting, having a seat at the table without necessarily being offered a chance to speak, or giving a personal testimony and then being sidelined for the rest of the meeting. They are also not supported in taking what they learn at meetings back to their communities.

Several of the Lesotho workshop participants were involved in working groups to establish a national network of people living with HIV/AIDS; some had also been involved in programs for which their support groups had external sponsoring. However, very few had been involved in any HIV/AIDS-related policy or program-level decisionmaking, design, development, implementation or monitoring. Most of the

activities carried out by both individuals and support groups were restricted to the community level or confined to activities related to HIV/AIDS care and support. Only one respondent was active at a policy advocacy level; she had represented people living with HIV/AIDS at the UNGASS on AIDS. She also sat on the CCM for the Global Fund and was involved in writing a proposal to the Fund. She is the founder of the support group People Living Openly with HIV and AIDS (PLOWA), which has done a lot of work on treatment literacy and adherence counseling.

None of the respondents had been involved in any policy or program formulation, design, delivery or monitoring around reproductive–health matters. Furthermore, the majority of respondents were not aware of any policies or programs that promote or specifically cater to HIV–positive women's sexual and reproductive rights, apart from addressing PPT. One respondent mentioned that many government policies are still in draft form. For example, the national policy on gender, which was written in 2001 but not yet finalized, is now felt to be out of date. In addition, participants in the focus–group discussion reported that they were *“completely lacking information about... reproductive rights and also accessing services.”*

The Lesotho respondents stated that training and capacity–building are priority needs to enable people living with HIV/AIDS to take up positions in government, contribute in decisionmaking fora with competence and confidence, and eliminate tokenism. Training is needed to provide skills in the areas of policy formulation, proposal writing, advocacy, program design, strategic planning, monitoring and evaluation, and documentation of best practices.

They also felt that there needs to be more transparency at the government level in terms of how money is used. For example, two percent of each government Ministry's budget is supposed to be used for HIV/AIDS–related work but little is known about how each Ministry uses that two percent (such as for activities or just to supply medications to civil servants at that Ministry).

The women in Lesotho also said media and information campaigns concerning HIV/AIDS should involve HIV–positive people in order to dispel negative images and to help get the message right. For example, local radio stations spread horror stories; in 2004, one station reported that condoms have worms and that women in hospitals had worms coming out of their vaginas. This story led to widespread fear and made community–education, awareness–raising and prevention work very difficult. Even the message that AIDS kills makes people very afraid and reluctant to learn their status.

Finally, the Lesotho respondents felt that more unity and collaboration is needed among people living with HIV/AIDS. In the current resource–scarce climate, there tends to be a lot of tension between organizations of HIV–positive people and this makes it difficult for them to lobby effectively or to form a critical mass.

Mexico

None of the respondents knew of instances in which women living with HIV had been invited to contribute to policy or program formulation and design. Some respondents commented that HIV-positive women can suggest ideas or make complaints about services by depositing them in suggestion or complaint boxes in some hospitals and clinics; the three women living with HIV did not know about this possibility, however. One of them said that this survey represented the first time anyone had asked her opinion about the topics discussed.

Poland

Among the organizations focused on AIDS in Poland, there is one officially registered organization dedicated to women living with HIV/AIDS and one NGO focused on the needs of children who have been infected. Both HIV-positive men and women have been involved in the creation of national HIV-related policies and programs. However, collaboration between the government and NGOs has centered around only two activities, neither of which have taken into account women's needs in particular: preparation of the National Program for People Living with HIV/AIDS and financing of projects submitted by associations of HIV-positive people to the National AIDS Center.

The people and organizations concerned with women and AIDS issues primarily focus on safe pregnancy and PPT; the main decisions about such programs are made by government institutions and scientific medical staff without the involvement of the beneficiaries. Up to 90% of the National AIDS Center budget is spent on providing ART to those who need it; the remaining 10% is spent on media campaigns, publications and grants for NGOs. HIV-positive women do not believe that enough funding is allocated to issues that affect them.

South Africa

The limited interviews in the clinic settings highlighted that policies and/or minimum standards on how to treat clients are not well-known. The principle of involvement and participation by those most affected has not filtered through into policymaking and decisionmaking processes.

Swaziland

In Swaziland, much of the counseling in VCT is done by people living with HIV. Although this work is important, the workshop participants did not believe this penetrates the consciousness of decisionmakers at the policy level, partly because the work is done on a voluntary basis and partly because it conveniently fills a gap that policymakers would otherwise have to fill. Workshop participants noted that the Business Coalition is encouraging workplace policies on HIV/AIDS but has only asked HIV-positive women to give personal testimonies for documents and programs. Participants also said: *"We are*

called at short notice and do not have time to prepare.” Organizations like UNICEF and the National Emergency Response Counsel on HIV and AIDS (NERCHA) work on behalf of people living with HIV/AIDS but do not involve HIV-positive people.

A workshop session that looked at implementation of the GIPA principle revealed a preponderance of activities by people living with HIV/AIDS at the community care level, especially in home and community-based care, awareness-raising and peer education. This means that there is plenty happening at the community level that could be used to influence policy or program formulation, but no-one is asking women *“what the right thing is to do.”* The net result is that women living with HIV/AIDS are so tied up with community-level service-delivery activities that they lack resources to take their skills to other areas of involvement, such as advocacy, research, or leadership and coordination. Furthermore, their resources and skills are kept within the community of people living with or most severely affected by HIV/AIDS, which in turn results in the further isolation of this community.

Only two of the 20 women had been involved at any level of policy or program development, and this was not specifically related to sexual or reproductive health and rights. In fact, the majority of participants who answered the survey were not aware of any sexual- or reproductive-health policies or programs designed with HIV-positive women in mind, other than PPT programs. One respondent said her organization had been involved in an ART pilot project, another had participated in the formulation of the National Strategic Plan on AIDS, and a third had taken part in a workshop on Policy, Legislation and Rights.

The Swazi women expressed considerable resentment about being “researched” without being involved in the design and implementation of studies, having those studies explained properly or seeing the their outcomes:

- *“People come to your home with a list on paper to get information from us. So we hide stuff. If it was my good friend I would be really open.”*
- *“Some of the information asked for was none of the business of the researchers and had they done anything to help us? We chase them away.”*
- *“They are not asking the right questions.”*
- *“We have research fatigue.”*

They stated a need to feel that they are creating and owning research and also believed they should be involved in more areas of research, for example, in the development of a microbicide that can be used to protect HIV-positive women.

The single most important aspect of meaningful involvement identified by the workshop participants was capacity-building: *“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.”* This could begin at the community level, within support groups

and among individuals and families, and could build up to capacity-building at the national or international levels.

Respondents commented that capacity-building also needs to be two-way so that governments, businesses and organizations learn how to create meaningful involvement: *“People think asking positive women to come and speak is enough, they need to be educated.”* Conferences and conventions were considered important because they hold skills-building sessions. Only one person living with HIV had attended the International AIDS Conference in Bangkok in 2004 from Swaziland, compared to 17 people from the government. The workshop participants felt that HIV-positive people should make up at least 60% of participants at conferences that are about HIV/AIDS and that they should be enabled to express their concerns there rather than just give testimonies.

6. FOLLOW-UP

The project partners were asked how they planned to use the information they had collected for advocacy and policymaking purposes.

In **Argentina**, FEIM intends to publish an article about the findings in their newsletter *DeSIDAmos*.

In **Kenya**, WOFAK left copies of the *Barcelona Bill of Rights* with respondents and continued disseminating copies to those requesting them after the project ended. They plan to hold a one-day meeting to disseminate the results for those who participated in the survey as well as stakeholders who could not participate but are interested in the subject matter.

ICW's report on the workshops held in **Lesotho and Swaziland** incorporated the findings from this project. The report was publicized through various e-mail listserves and made available through the ICW website. The report was also sent to the project participants, their support groups, other allies, and the Action Aid-managed Support for the International Partnership Against AIDS in Africa project (SIPAA). ICW will post this final overall project report on their website and disseminate it widely through ICW global networking channels. ICW is currently following up the Swazi workshop with a project in collaboration with the US-based POLICY Project that focuses on capacity-building for advocacy.

In **Mexico**, PECAC prepared an overview of the survey answers to share with those who were interviewed; they also plan to give them a copy of the final overall report prepared by Ipas. PECAC hopes to present a paper on the project at the National Conference on HIV/AIDS in December 2005.

PECAC has already used the study findings to prepare a grant proposal for the Ministry of Social Development (SEDESOL) to publish materials specifically for women living with HIV, to organize workshops with specialists who can speak on the issues that are not being addressed (for example, possible interactions between ART treatment, drugs for opportunistic infections and hormonal contraception methods), and to launch a campaign to promote the female condom.

The Federation in **Poland** intends to make its report available to NGOs in the country and to announce the main results of the study through an article in the press.

In **South Africa**, GAF's feedback session for the women who were interviewed enabled them to check their findings and develop a strategy for action. A summary of the country report will be distributed to participants of each support group and a session

will be arranged to report back in person to each group. The groups' ideas and input will be incorporated into a final country report, which will be used for advocacy and lobbying.

At the global level, **Ipas** will report on some of the MDG benchmark-related findings in an article for the *Journal of Health, Population and Nutrition*. Information about the project design, implementation and lessons learned will be shared through a presentation at the 12th Priorities in Reproductive Health and HIV Conference, to be held in South Africa in October 2005. In addition, Ipas will publicize this report through e-mail listserves, feature it as a downloadable document on the Ipas website, and use the findings for advocacy purposes and in other publications regarding HIV/AIDS and reproductive rights.

7. CONCLUSIONS AND DISCUSSION

7.1. WERE THE AIMS FOR THE MONITORING TOOL FULFILLED?

As noted in the Introduction, we hope that use of the monitoring tool will contribute to four main aims.

Provision of a simple means of collecting information on MDG-related issues

The project showed that provision of the monitoring tool as a framework, together with some very simple guidance on implementing a data-collection exercise, was sufficient to enable partners in very different countries to collect information on the same topics.

While some more guidance might have been preferable — such as examples of how to adapt or reword sample questions for different audiences or more guidance on how to classify respondents — the project description gave the partners freedom to decide what types of data collection best suited their needs and situation.

Sharing information on how the various partners conducted their projects was useful in providing the partners with ideas about other approaches they might use themselves in a future round of data collection.

Showing the relevance of MDG 5 and MDG 6 to daily reality and work at the local level

In Kenya, the data collectors noted that NGO staff approached for the project did not know how MDGs 5 and 6 affect them or women living with HIV in daily life. It became apparent to them, however, that the issues to be tackled under those MDGs are extremely important for women affected by HIV/AIDS and their service providers in both the governmental and NGO spheres.

PECAC commented that their project was the first to focus on the study topics in Chetumal and the greater municipality of Othón P. Blanco. They considered the findings to be very valuable evidence of the kind of health services that are provided to women living with HIV. In their opinion, the project results form a good basis for concrete community action projects to address the almost total lack of attention to the specific needs of women living with HIV.

Respondents in all countries wanted to receive the findings of the data-collection exercise and a considerable number said that the exercise had opened their eyes to issues they had not yet thought about but which are nonetheless important.

Contribution to NGOs' knowledge base and skills for advocacy

Project partners: This project presented the staff and collaborators of some partner organizations with their first opportunity to engage in a simple research/data-collection exercise. This was the case, for example, for some research team members in the GAF project:

"We were all initially excited at the opportunity to learn new skills, and to expand our skills, and to take part in creating knowledge about our own experiences and those of women and girls in our community. The world of research was something that we previously thought of as being for 'academics' and not for ordinary women.

At the onset of the research, we were realistic about the state of the health-care system and based on our own experiences, and that of women and girls we knew, we were aware of the negative treatment women suffered at the hands of the health-care worker. However, the realities of what we heard and saw were far worse than we imagined and our initial excitement was soon replaced with negative emotions. The debriefing session at the data analysis workshop provided a platform to address the feelings and emotions that hearing women's stories had left with us.

As researchers, women and activists, we felt sad, depressed and deeply concerned about the experiences of women living with HIV and AIDS. We found it difficult to deal with the depths of grief and pain experienced by women, their lack of knowledge and access to any rights. Women's sense of powerlessness was overwhelming, and for many women there is often a lack of choices. In spite of this, we were inspired by some strong voices — with women standing up to the abuse they faced in different sites of struggle.

We were shocked at the lack of apparent knowledge about HIV/AIDS and other issues of the health-care workers. Why, after 20-plus years of an epidemic, are women and men treated so badly? Why are women's lives so difficult? How does the system that is supposed to be about 'health' and 'care' work so strongly against our wellbeing? As researchers, we feel and understand that we have a responsibility to all women who are trying to access sexual and reproductive health and rights. We have a responsibility to the women whom we interviewed in particular, to ensure that the issues raised in this project do not remain only in this document. We are committed to take the issues forward so that they are listened to, believed and acted upon at both a policy and practice level."

The project convinced the South African team that women's empowerment through producing knowledge is critical as an advocacy tool. They felt that knowledge

production and creation must be demystified, democratized and reshaped, so that it is a tool for change and transformation in everyone's hands, not just in the hands of a few.

Project coordinators and staff in the other countries also expressed appreciation for involvement in the project.

- *"It has been a learning experience and an eye-opener for me as an individual and WOFAK as an organization. It is evident that a lot of us are ignorant on issues that affect us directly and we need to lobby and advocate for better policies on issues pertaining to sexual reproductive health."*
- *"It's very important for us [FEIM] to share the other findings to compare with ours and include in the article to be published."*
- *"On a personal level, I learned a lot, not only on topics such as the laws on legal abortion and legal adoption, as well as information on emergency contraceptives, but I was also able to see more directly and clearly certain aspects of the problem of HIV/AIDS in my community that are not always evident. The results will help PECAC to reformulate its policies, to make sure that all these issues are included in our prevention workshops, and to publish new written materials, such as brochures and posters, with the information that is so lacking. It came as a surprise to me that the only written materials on HIV/AIDS prevention that several institutions have are the ones published by us. This is rewarding in the sense that it shows we are fulfilling an important need, but it also puts on us a greater responsibility in making sure that all the issues concerning women with HIV are made public and are widely spread."*

Project respondents: As well as the project team members, respondents also found this to be a valuable exercise for themselves and their organizations. For example, in Kenya, seven HIV-positive and two NGO respondents said completing the questionnaire was an educational activity, and four women living with HIV spontaneously commented that it was empowering. A few Kenyan respondents also remarked that it showed they needed more training and informational materials.

In Swaziland, the general response was that the survey had been too long. Some of the women said there was a lot they felt they didn't — but should — know about. Consequently, they had invested considerable time in finding out more through the Internet or other means about some of the areas with which they were unfamiliar. As one woman said: *"Most of the questions were unfamiliar — I had to do a lot of research — it took two days to complete it."* Nevertheless, the members of the focus group felt that these were important issues for them to know and think about, and that it was therefore a worthwhile though lengthy exercise.

- *"It was very long but touching on issues that pertained to our own needs; I felt Oh! I need to know about these."*
- *"It was too long but interesting — I knew about most of the things but it was a wake-up call."*

- *“I’m involved in distributing drugs, but I didn’t know the answers to some of the questions. It made me realize that we take a lot of things for granted (e.g. violence against women) — that we don’t know about our rights. And Pap smears — I didn’t know about the importance of them.”*

In addition, the participants reported that the exercise had made them think about the difficulties faced by more marginalized groups of women, such as rural women and HIV-positive women with disabilities.

The feedback on the survey itself by the respondents in Lesotho was remarkably similar to that given by the Swazi focus-group members. Some women felt somewhat intimidated by the length of the questionnaire and the fact that they didn’t know the answers to all the questions.

- *“It felt like a test.”*
- *“[I felt] intimidated — like I should know the answers but I didn’t.”*
- *“Some of the declarations I had no idea about, but I felt that as a positive woman I should have.”*
- *“[It] made me feel like I’d been ignorant — it gave me a tough time.”*

Some respondents were not aware of some things mentioned in the questionnaire and reported feeling like *“I’ve just woken up.”* Nevertheless, again several women said they felt it had been a useful thing to do.

- *“It was a good exercise because it made us feel like we need to learn more.”*
- *“[We] need to read more, need to know more about these things — I wanted to do research on them.”*

Collection of data on similar issues across time and across countries and regions

While the ways in which the project partners reported their data differed considerably, it was possible to distill some differences and similarities between the situations in the different project settings. We hope that repeating the data-collection exercise in the same places in about nine months may point to at least some minimal changes, for example improved knowledge about rights and availability of services.

7.2. CHALLENGES FACED IN CARRYING OUT THE PROJECT

Overall project design and coordination

A major challenge for Ipas in carrying out this project was to find partners willing to participate at short notice. A very modest budget for the project was approved in the late summer of 2004, and initial contacts with potential partners were made. Some

NGOs which were interested ultimately could not participate, so new contacts had to be made, all of which cost time. We hoped that data collection could begin at the end of 2004, so that the country reports would be done by May 2005 and a summary report could be ready in time for the UN General Assembly's meetings with civil society about the MDGs on 22 to 24 June 2005.

Only two partners were able to complete the project according to the original schedule, however, and the final country report was only received by Ipas on 23 June 2005. The summary report was finalized and approved by all project partners by mid-August so that publication on the Ipas website coincided with the World Summit meeting at the UN General Assembly on 14–16 September 2005.

Another reason we wanted to ensure the project was done in the first half of 2005 was so that we could repeat the data-collection exercise — albeit with improved data-collection methods — in late 2005 to early 2006, compare the results within and across countries over time, and present findings at the XVI International AIDS Conference in Toronto (August 2006).

Country-level challenges

The project partners faced various challenges in collecting the data. Logistical problems were related to the time limitations of the respondents and researchers. In Kenya, the data collectors sometimes had to make up to three visits to a person or facility in order to deliver and collect a completed survey, making the exercise costly in terms of transportation and time. The interviews in Argentina with some health-service providers and government representatives also had to be rescheduled a number of times.

In Mexico, some people approached for interviews refused to participate in the project. They included nurses at one hospital, several doctors from urban health centers, and the staff of an organization that deals with survivors of rape and other forms of sexual violence. They stated that they needed clearance and permission from their superiors and referred PECAC to the directors of the institutions for this.

In South Africa, GAF sent a letter to the Superintendent of Health asking for permission to interview clinic and hospital staff because staff in these institutions refused to speak with them without such written authority. At the end of the data-collection process, they received an unfavorable response stating that the Department of Health could not see any value in the study.

Respondents in some countries — Kenya, Lesotho, Swaziland — found that the sample questionnaire had too many questions. On the other hand, other project partners suggested either splitting up some questions to make them clearer (for example, by asking separate questions on whether IEC materials on contraceptives cover drug

interactions, EC, and so on) or adding questions to explore some issues further. For example, ICW suggested adding questions on the following specific topics, some of which are actually covered in the monitoring tool:

- Barriers to accessing reproductive–health services (in general and for young, rural and disabled women and widows in particular)
- Barriers to accessing contraception
- Barriers to accessing abortion
- Pap smears: are health service providers aware that cervical cancer is a well–documented killer of women infected with HIV and do they give appropriate recommendations to women who are HIV–positive about the importance of regular smear tests?
- Availability and accessibility of women–only or women–centered clinics (visiting times, etc.)
- PPT as a treatment and care service rather than simply as a prevention measure (including issues of healthy conception, planning for having a baby, counseling, nutrition and safe delivery)
- Infant feeding options for HIV–positive women
- Assisted conception
- Sexual– and reproductive–health services and materials tailored for young women living with HIV/AIDS

The Federation advised asking more questions about pregnancy and HIV–positive motherhood because many HIV–positive Polish women want to become mothers. They also commented that the issue of abortion is very important and should be examined, taking into account the reasons why HIV–positive women may choose to have an abortion and exploring the social, medical and legal difficulties connected with their decision.

PECAC commented on the order in which the sample questions were presented. The first question asked whether women living with HIV are involved in policy and program formulation, implementation and evaluation. Because this has not yet happened in Chetumal, some respondents found this question intimidating or embarrassing, which set a negative tone for the interview. PECAC suggested beginning the data–collection exercise by discussing the *Barcelona Bill of Rights* and other human–rights documents, as this would create a framework in which other questions could then be addressed.

FEIM and PECAC found that some questions — for example, those on PEP — had to be explained to respondents. ICW and WOFAK suggested rephrasing some questions so that the language used was simpler and easier to understand for respondents whose first language is not English. Because some of the women involved in the ICW workshops were illiterate and non–English speakers, ICW suggested including translation/ interpretation possibilities in a future project. ICW and PECAC also suggested rephrasing

sample questions so that they were open rather than closed in order to elicit more information from respondents.

Some other challenges were related to the content matter covered by the project. PECAC found that some respondents were reluctant to answer certain questions, sometimes because they did not want to commit themselves to having the answers recorded. Respondents in Lesotho and Swaziland commented that answering the questions made them feel ignorant. The data collectors in Kenya also noted that there was a relatively high level of ignorance concerning sexual and reproductive rights among their respondents.

Various partners encountered respondents who refused to participate for fear of repercussions if they did not receive supervisors' approval or for fear of recrimination. In Kenya, for example, some respondents withheld information because they were afraid it would be used against them in some way.

7.3. LESSONS LEARNED CONCERNING THE PROJECT LOGISTICS

All of the project partners expressed interest in repeating the data-collection exercise at the end of 2005 and early 2006 in order to see if any changes have occurred. In that light, we are considering ways to improve the project process and experience.

Ipas would encourage partners to exercise greater freedom in adapting sample questions regarding wording and the order in which questions are asked during interviews. Adding some explanations to questions could be useful, particularly if surveys are left behind for respondents to complete on their own. In Kenya, for example, it was unclear whether respondents' answers pertaining to "their organization" referred to WOFAK or the other organizations for which they worked.

Organizing a one- or half-day workshop on data-collection methods, as GAF did, could be useful in other countries. For example, data collectors could be encouraged to offer explanations to respondents who are uncertain about the meaning of questions.

The partners delivered very different types of reports: brief summaries, reports with highlights and papers with quantitative representations of questionnaire responses. More guidance from the project coordinator on the format for presenting findings would make comparisons and summarization for the overall report easier. This wish must be balanced against the need for partners to present their findings in a format that serves their own particular needs.

Women in Swaziland mentioned that they were suffering from research fatigue; this may be the case for HIV-positive women elsewhere as well. We should avoid adding to their

sense of being over-researched and continue to ensure that they are clear on how the project findings will be used. When the country and overall project findings are reported back to respondents, it will be useful to ask their ideas on how the next round of data collection should proceed.

7.4. KEY PROJECT FINDINGS

Availability of VCT and PEP

Although it could be assumed that the respondents in the various projects would be well-informed about HIV/AIDS issues such as VCT and PEP — especially because many HIV-positive and other respondents are educators and service providers — it became apparent that many of them lacked pertinent knowledge.

According to many respondents, VCT centers are becoming available in most large urban centers, but access to VCT in rural areas still leaves a great deal to be desired in some countries. Respondents in Poland and Swaziland noted that many women seem to be dissuaded from having an HIV test because they assume that they are not at risk — because they are a faithful spouse or don't belong to one of the “risk groups” highlighted in AIDS prevention messages — or because they are afraid of the consequences should others learn of their positive HIV status. As a consequence, it appears that many, if not most, women in all the project countries only learn of their HIV-positive status after antenatal testing.

In some project sites, PEP is available to health (and other) professionals who suffer occupational exposures to HIV; in others, PEP may be named in health regulations but not actually be accessible. In almost all cases, it does not appear that good statistics are available on how many health professionals have accessed PEP.

Provision of PEP for survivors of sexual assault appears to be a relatively rare occurrence in all the project countries except South Africa. While some respondents thought PEP might be available for rape victims, almost none mentioned knowing of women who had actually used it and the project partners were unable to obtain any registered data on PEP provision related to sexual assault.

While the South Africa project did not discuss PEP availability — since their respondents were almost all already HIV-positive — they did note that new types of violence against women living with HIV are being perpetrated by their male partners: breaking condoms so that women cannot protect themselves against reinfection and pregnancy, and appropriating the women's ART supplies so that they cannot benefit from treatment.

Fertility regulation in the context of HIV/AIDS

Women's access to general information about family-planning and contraceptive supplies appears to vary between and within the countries where the projects took place. Family-planning associations and governmental reproductive-health programs often have non-HIV-specific printed materials available, and access to contraceptive supplies in urban areas is fairly good (with Argentina and Poland as exceptions). However, the range of contraceptive options may be limited and little information appears to be available regarding contraception in the context of HIV infection. In essence, the projects found that health-care providers' preferences still determine how much and what kind of information women receive about contraceptives. When family planning is discussed with women living with HIV/AIDS, emphasis continues to be placed on use of the male condom.

Reports have emerged in recent years that some ART programs may require women to use provider-defined contraceptive methods in order to be eligible for treatment. Some focus-group respondents in Kenya mentioned that they are asked to use condoms, and health-care providers in Mexico said they promote condom use because it can help prevent infection with new strains of HIV. It was only in Lesotho that one HIV-positive woman said she had been asked to use either injectables or an IUD so that her health-care providers could supervise her fertility control. Women in Poland are asked to tell their physicians when they become pregnant so that their ART regimens can be changed if needed (a few antiretrovirals are contraindicated for pregnant women).

Knowledge of and access to EC is still limited in the areas assessed by the projects. In some cases, there is active opposition to making it more widely available—for example, in Argentina and Poland—while in other places bureaucratic and financial factors seem to impede increased availability within the health sector.

The topic of abortion—or even postabortion care—appeared to be avoided by respondents in Argentina, Kenya and Poland. A few health-care professionals in Mexico spoke about abortion being taboo and illegal, although it is permitted in cases of rape, fetal malformation and danger to a woman's health in the state of Quintana Roo. Respondents in Lesotho and Swaziland mentioned that some women travel to South Africa for legal abortions. The Swazi women expressed concern about a lack of postabortion care services in rural areas and were further troubled by reports of abandoned babies and infanticide by women who could not cope with having children from unwanted pregnancies. Even in South Africa, which has liberal legal indications for pregnancy termination, the HIV-positive respondents noted that women are dissuaded from accessing an abortion and may suffer abuse if they are able to obtain this legal medical procedure. Reports of such abuse included being handed a fetus for disposal and being "*granted*" a TOP only after agreeing to be sterilized.

Parenting options for HIV-positive women

At least some respondents in Kenya, Lesotho and Swaziland said they knew of HIV-positive people who had adopted children; it was unclear whether the children were also HIV-positive. In Poland, one NGO is actively mediating so that such adoptions can take place, although there it seems that only children who are themselves HIV-positive are placed with adults who are living with HIV. In Mexico, governmental regulations prohibit adoption by seropositive persons.

In the projects that touched on the issue of assisted conception, the respondents indicated that this option is scarcely available to people living with HIV; only one case in Poland was mentioned where a couple was able to make use of assisted reproductive technology.

HIV/AIDS-related stigma and discrimination

Although we have passed the 20-year mark for the worldwide HIV/AIDS pandemic, it is apparent that considerable numbers of health-care professionals still have insufficient information about HIV/AIDS and the risk of occupational exposure to HIV infection. This is contributing to fear and subsequent stigmatization and discrimination of patients and clients who are living with HIV.

While some respondents (and project data collectors) did know of health facilities that provide high-quality care, all the projects reported that stigma and discrimination against women living with HIV/AIDS persist within the health-care sector. The extent to which this still takes place may be much greater than is often assumed, particularly as some HIV-positive researchers were surprised, and sometimes shocked, at the examples of abuse reported.

Many types of discrimination are remarkably similar across countries and regions. HIV-positive women in Africa, Europe and Latin America are facing denial of treatment and care, humiliating and stigmatizing attitudes, and breaches of confidentiality. This is particularly the case among health professionals who are not specialized in HIV/AIDS care. The South African project noted a new type of discrimination that is taking place: using women's participation in clinic-based ART support groups as a precondition for granting treatment.

Particularly troubling is the fact that discrimination is often reported regarding obstetrical and gynecological care. Given the enormous amount of attention paid to PPT programs in the last five years, we might have expected that human-rights violations in this area of health care would have been minimized. It is perhaps the continuing emphasis on PPT rather than comprehensive care for pregnant women that has contributed to this situation and which, if it continues, may yield more cases of rights violations in the context of opt-out testing (which is being heavily promoted for

antenatal care in many countries). While women theoretically should be able to decide freely to refuse routinely offered HIV tests, human-rights scholars and activists are warning that opt-out systems may easily turn into systems that impose HIV tests since many patients are reluctant to challenge advice or instructions from health-care providers. Issues that require attention in this area include obtaining truly voluntary and informed consent, safeguarding confidentiality and ensuring proper counseling for women to be tested [64].

HIV status has now become a reason for exclusion from and denial of services. Stigma and discrimination against people, especially women living with HIV, have become the new apartheid. This new apartheid affects both men and women living with HIV and AIDS in accessing treatment for opportunistic infections, antiretroviral therapy, care and support. One way that we as women experience this new apartheid is through the control of our ability and opportunity to access our sexual and reproductive health and rights.

— Gender AIDS Forum

Human rights as a framework for provision of programs and services

Familiarity with the *Barcelona Bill of Rights* was limited in all of the project countries, although respondents expressed interest in the document and the institutional representatives said they were willing to display or otherwise make copies available for their clients. Though some health-care providers said they knew of the international guidelines on HIV/AIDS and human rights, it was not always clear if they were referring to the guidelines produced by UNAIDS and the UN High Commissioner for Human Rights.

The collected data indicated that, while national government programs and hospital regulations may endorse rights, this does not automatically translate into observance of those rights at the service-delivery level. Compliance with rights depends on enforcement by provincial and municipal authorities, funding for programs (which affects availability of supplies, equipment and sufficient staff), and positive attitudes and willingness on the part of service providers.

The large majority of respondents in all countries were interested in receiving more information about rights. However, neither health-care providers nor women living with HIV/AIDS seemed clear on how such documents could be relevant to their work environments and daily lives.

In South Africa, where treatment-literacy programs have been widely promoted to empower women living with HIV to act on behalf of their own health, some women have been insulted for knowing and understanding their needs and the correct options for

treatment. Health-care workers often don't have this information themselves, or they feel threatened by treatment-literate patients.

Health-care workers are regarded with great respect by women and other community members, and they are expected to be responsive to the needs of the community. When they fail to do this or when they act in ways that contradict their caring role, community members are often unable either to consciously identify this as a violation of their rights or to assert their rights (for example, through direct communication with the health-care provider or by initiating a complaints procedure). Given that they often occupy a subordinate position in society, women are especially likely to feel subservient to health-care workers and unable to assert themselves. Women living with HIV/AIDS are in an even more complex situation when they are stigmatized and marginalized by society, including by health-care providers.

Involvement of HIV-positive women in reproductive-health policies and programs

Some formal mechanisms exist through which women affected by and living with HIV/AIDS are granted a place on decisionmaking bodies, but respondents in all countries indicated that this involvement often continues to be tokenistic. They also asserted that many women lack the skills and back-up support needed to be effective advocates in such bodies. The women living with HIV in Argentina, Lesotho, Poland and Swaziland in particular commented on the corresponding need for capacity-building in this area.

On the whole, the projects indicated that women living with HIV/AIDS are **not** involved in policy and program formulation, design and evaluation at the local or national levels. When respondents spoke of HIV-positive women's involvement in programs, they invariably referred to women who help implement programs and services. Time and again, the women themselves, as well as the representatives of government agencies and NGOs and the health-care providers, acknowledged the valuable contributions of HIV-positive people — usually as volunteers — in terms of prevention activities, counseling, community support, home-based care and, more recently, ART treatment support. In reality, the GIPA principle is interpreted to mean “a greater role for people living with HIV/AIDS in delivering services.”

7.5. RECOMMENDATIONS

Based on the key findings from this monitoring tool project, the following recommendations can be made regarding the measures that are needed to ensure that MDGs 5 and 6 are ultimately achieved for women affected by and living with HIV/AIDS.

Expand and intensify training for health professionals on occupational risks of HIV infection in conjunction with capacity-building on the rights of people living with

HIV/AIDS. Such training should emphasize that health-care providers have a right to have sufficient supplies available to observe universal precautions for themselves and their patients (such as gloves, disposable needles, and sharps disposal boxes). Health systems must also make PEP available to providers.

Training sessions and workshops on the ethics of providing services to people living with HIV should incorporate HIV-positive women as paid facilitators, since guided dialogues between them and providers can contribute to changes in attitude and subsequent treatment of clients and patients. HIV-positive women who have had treatment-literacy training can help explain why it is important for patients to be partners with health professionals in implementing treatment.

Such training sessions need not be lengthy. Ipas, for example, conducted a half-day session on rights with health-care providers in Vietnam in which they quickly became able to identify violations of rights and to indicate what could be done to improve the observance of rights. In another half-day session, providers heard the perspectives of HIV-positive women on service provision and received feedback from them during counseling role plays; this contributed to their empathy for HIV-positive clients and their desire to know more about HIV/AIDS in order to improve the care they provide.

Employ women living with HIV in prevention and VCT programs as paid staff. Many programs involve HIV-positive women (and men) in disseminating prevention messages — use condoms, get tested, be faithful to your partner — through talks and personal appearances during educational activities. However, it does not seem that women living with HIV are often consulted about what kinds of messages would have drawn their attention before they learned their serostatus. For example, what messages might have motivated them to have an HIV test sooner than they did? Involving HIV-positive women in the formulation of prevention policies and messages is very important and they should be paid for providing their life-based expertise and input.

One factor that is impeding the establishment of more VCT sites throughout countries is a lack of trained counselors. Many health-care professionals already carry heavy workloads for meager wages and may be reluctant or unable to add counseling to their daily tasks. Trained HIV-positive persons have proved to be excellent counselors in many countries. Health systems need to stop relying on them as volunteers; rather, they should be employed as staff so that services become more widely available.

Prepare and publish materials on family planning, contraception and options for avoiding and dealing with unwanted pregnancies in the context of HIV/AIDS. While it is reasonable for women living with HIV to be informed about the double protection against reinfection and pregnancy offered by male condoms, they should also receive more information about other contraceptive options. Such information should address concerns related to HIV/AIDS, such as which contraceptives might be preferable for

women in their situation, and the potential interactions between hormonal contraceptives and drugs for opportunistic infections and ART.

Options for avoiding unwanted pregnancies should also be mentioned, including EC and safe abortion for indications considered lawful in each country. Given the high prevalence of sexual violence experienced by women living with HIV, for example, it is important that they know whether pregnancy termination is allowed in cases of rape or when a woman's health is endangered.

While such materials can be developed through collaboration between governmental AIDS and reproductive-health/family-planning programs, NGOs can also play a role.

Advocate for increased availability and accessibility of EC, PEP and safe, legal abortion.

Both governmental agencies and NGOs need to ensure that HIV-positive women and men are informed about all the available options that can help protect against HIV reinfection and unwanted pregnancy. Information provision alone is not enough, however; women's awareness and understanding of their rights will remain meaningless if services are not available. Lobbying and advocacy on these issues with NGOs, through the media and toward policymakers is an important step toward expanding women's options to exercise their rights to health and to decide whether and when to have children.

Advocate and lobby for the possibility of HIV-positive men and women adopting children.

While women living with HIV can reduce chances of HIV transmission by participating in PPT measures, they can also avoid perinatal transmission by not becoming pregnant at all. Many HIV-positive women, particularly younger women, do indeed want to become pregnant and bear biological children. However, some women are interested in adopting children and this option should be possible.

Organizations working on AIDS should ascertain whether legal restrictions on adoption would prevent HIV-positive people from adopting and, if so, whether these restrictions are reasonable. NGOs and government agencies entrusted with adoption programs should collaborate with associations of people living with HIV to discuss how programs can ensure that HIV-positive people are not automatically disqualified as prospective adoptive parents because of their infection. Adoption as a parenting option should be included in informational materials on sexual and reproductive health for people affected by HIV. Associations of people living with HIV can also begin disseminating information about successful adoptions through newsletters and websites and at conferences; cases from one country can serve as examples and inspiration for people in other countries.

Disseminate information on human-rights standards in practical terms relevant to recipients' work and lives. Informing people affected by and living with HIV, service and

health-care providers, NGO staff and policymakers about sexual and reproductive rights in the context of HIV/AIDS is a sorely needed intervention in many countries.

Disseminating documents such as the International Planned Parenthood Federation's summary guide to sexual and reproductive rights [72], the *Barcelona Bill of Rights*, and the *International Guidelines on HIV/AIDS and Human Rights* — as well as locally produced materials on human rights — is an essential and fairly simple step to take. It does depend on the willingness and financial capacity of advocates to obtain, translate, reproduce and distribute the documents to all parties concerned. If funds are limited, such documents can at least be photocopied to leave as display copies with NGOs, in waiting rooms of governmental agencies, and at VCT sites, hospitals and clinics.

Mere dissemination of human-rights documents is nevertheless insufficient to help people understand how these rights apply to their lives. They need to understand which international rights treaties their governments have ratified, how those rights can be claimed through laws and regulations (which requires lobbying of lawmakers), and how private citizens can bring forward complaints when their rights are violated. NGOs need to help HIV-positive women identify where complaints can be addressed and support them in following up on those complaints, which can be a lengthy process. This can include instructing HIV-positive women on how to lodge complaints with hospital and clinic directors, how to submit cases for follow-up with local human-rights commissions and ombudsmen, and how to find lawyers who can take well-documented cases to court if necessary.

Pressure can also be put on governments to speed up compliance with human-rights treaties by preparing reports for the international committees that monitor treaty compliance; such reports can come from individual citizens and NGOs. Associations of people living with HIV/AIDS and NGOs can also lobby the individuals and institutions that accept complaints about human-rights violations to actually deal with those complaints in a timely fashion.

Information about these measures can be disseminated through articles in newsletters and journals, through brochures and leaflets, and through capacity-building sessions for both service providers and clients/patients. When people understand that there are practical steps they can take regarding discrimination and rights violations, these rights can leave the realm of theory and enter into the reality of daily life.

Promote capacity-building and skills-building for women affected by and living with HIV/AIDS so that they can participate meaningfully in advocacy and policymaking. Many of the women who have direct experience with the HIV/AIDS epidemic and could contribute invaluable information to inform and direct policies and programs have had no formal training on translating that experience into advocacy and action. The projects indicated that women want a place at the decisionmaking table but that this must be

achieved in a meaningful way so that their voices are actually taken into account in the development of policies and programs.

NGOs and universities can provide a wealth of information on advocacy and policymaking strategies and procedures, and can contribute greatly to enhancing women's skills. One way is to engage more HIV-positive women in gathering information and evidence on which advocacy and community action can be based — similar to what was done in the projects in Kenya and South Africa, where the research teams included women living with HIV. The respondents in Swaziland also recommended that HIV-positive women be more involved in designing research studies and evaluating what can be done with the findings.

In addition to the training courses and workshops on advocacy and policymaking that are usually recommended, another approach to explore is mentoring. More university and NGO staff can offer women living with HIV a chance to collaborate on their research as interns, with a clearly stated objective of the women gaining skills to use in other capacities. NGOs can mentor and guide women in developing skills such as proposal writing, program design, strategic planning, documentation of program achievements, and monitoring and evaluation.

As the respondents in Swaziland noted, capacity-building also needs to be a two-way process so that governments, businesses and organizations learn how to create meaningful involvement of women affected by and living with HIV/AIDS. Asking HIV-positive women to cofacilitate such capacity-building would be a step in the right direction.

7.6. MARKING PROGRESS TOWARD MDGs 5 AND 6

The data collected by the different projects using the monitoring tool on HIV, reproductive health and MDGs 5 and 6 showed that much remains to be done if these MDGs are to be realized.

If maternal mortality is to be reduced, women need to be able to make fully informed decisions about pregnancy and parenting. This means they need relevant and specific information on contraceptive methods and all their fertility-regulation options, including ways to avoid and end unwanted pregnancies, such as EC and safe, legal abortion. They need to know whether assisted conception is available and what else they can feasibly do to have safer pregnancies. People living with HIV also need to know whether legal adoption can help them fulfill their parenting desires.

If HIV/AIDS is to be combated in a meaningful way, more attention must be paid to prevention measures relevant for women. For example, given the high levels of violence

against women that still exist around the world, PEP must be made available for survivors of sexual assault.

Women can be encouraged to access VCT by prevention messages that focus on everyone's vulnerability to infection, not only on that of "risk groups." However, VCT sites and services must be rapidly expanded, especially in more rural areas, and must involve HIV-positive women as co-managers, counselors and evaluators in order to improve their quality and relevance for other women.

Women also need to know that engaging in VCT will produce benefits. They will continue to avoid testing — or even avoid obstetric and gynecological services where testing is routine or opt-out only — if they fear humiliation, denial of care or abusive treatment when family members or providers learn their HIV status. If women believe that acknowledgment of a positive HIV status may instead benefit the health and well-being of themselves and their families — for example, because they will be able to access ART and prolong their survival— they may be more willing to come forward for testing. This of course requires more rapid expansion of ART treatment and treatment-literacy programs.

One of the most important interim MDG benchmarks to be accomplished is eradicating HIV/AIDS-related stigma and discrimination. Although an increasing amount of work has focused on defining stigma and discrimination in the field of HIV/AIDS, the experiences of the respondents in Argentina, Kenya, Lesotho, Poland, South Africa and Swaziland indicate that much more needs to be done to promote positive attitudes, reduce fears and educate people on how they may — even unconsciously — be sustaining stigma and discrimination. Progress in this area will undoubtedly support and enhance all other efforts to improve the sexual and reproductive health of people vulnerable to and living with HIV/AIDS.

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APPENDIX 1: SAMPLE CONSENT FORM

Our organization is collecting data to help monitor progress toward achieving two of the Millennium Development Goals (MDGs) in relation to reproductive-health services for women affected by HIV/AIDS: MDG 5 on reducing maternal mortality and MDG 6 on combating HIV/AIDS.

I would like to ask you some questions regarding the services that your organization/facility provides to women living with HIV/AIDS. A few organizations in other places are asking similar questions of organizations and facilities in their localities. The findings from all the data-collection exercises will be synthesized in an overall report to be prepared by Ipas, an international NGO that works on women's reproductive health {contact person: Maria de Bruyn, Ipas, 300 Market Street, Chapel Hill, NC 27516, USA; e-mail: debruynm@ipas.org}.

I estimate that it will take about 20–30 minutes of your time to complete the interview.

The benefits which may reasonably be expected to result from this inquiry are that we will gain a snapshot of some reproductive health-care services available locally for women affected by HIV/AIDS. This information can prove useful to government agencies entrusted with implementation of the MDGs.

There are no financial costs to you for participating, nor will you be reimbursed for your participation. Please understand that your participation is voluntary. You have the right to withdraw your consent or stop your participation at any time without penalty. You also have the right to refuse to answer particular questions.

Every effort will be taken to protect your identity. Reports on the results will describe the type of organization you represent (department of a hospital, clinic service, NGO, organization of people living with HIV/AIDS). Though I will keep the name of your organization and your own name confidential, there is a risk that your organization might be identified by people familiar with organizations in your community.

AGREEMENT STATEMENT

I have read and understand the information presented here and I freely give my consent to participate in this data-collection exercise.

Signature

Date

APPENDIX 2: SAMPLE QUESTIONNAIRE

1. Does your program require that HIV-positive women's associations are involved in policy and program formulation, implementation and monitoring/evaluation? If so, how are these associations involved?
2. If it is not required, does your program receive input from HIV-positive women in some other way? If so, what does this involve?
3. Are you familiar with the *Barcelona Bill of Rights*? If so, do you have copies on display or available for clients?
4. If not, would you be willing to display a copy in your facility?
5. Are you familiar with the guidelines on HIV/AIDS and human rights issued by UNAIDS and the Office of the UN High Commissioner on Human Rights? If so, do you have a copy available for clients?
6. Does your program promote any other documents on sexual and reproductive rights? If so, which documents are those and how are they promoted?
7. Does your organization/program have available materials on contraceptives that also address issues of concern to people living with HIV (e.g., dual protection, use of emergency contraception, breakthrough bleeding or spotting, possible interactions between hormonal contraceptives and drugs used to treat HIV and opportunistic infections)?
8. If so, which of the issues just mentioned are addressed?
9. If you don't have such materials available, why not?
10. Does your organization/program have available materials specifically for women living with HIV that discuss options for avoiding unwanted pregnancies, such as female and male condoms, microbicide research, emergency contraception and safe legal abortion?
11. If so, what kinds of materials are available?
12. Does your organization have other materials available on options for avoiding unwanted pregnancies?
13. Does your program/facility offer emergency contraception without a prescription or as a prophylactic measure?
14. Does your facility provide VCT services or referrals to such services?
15. Does your antiretroviral treatment program require women to use certain fertility regulation methods as a criterion for enrolment? If so, which methods and why?
16. Does your facility provide post-exposure prophylaxis (PEP) for survivors of rape and incest or referrals for PEP?
17. How many rape/incest survivors have received PEP at your facility within the last year?
18. Does your organization address the possibility of people living with HIV/AIDS becoming legal foster or adoptive parents? Why or why not?
19. Do you know of any people living with HIV/AIDS who have legally adopted children?

APPENDIX 3: LOGISTICAL INFORMATION FOR THE PROJECT COORDINATOR

To assist in preparation of the final summary report, the project partners were asked to answer the following questions.

1. Did you involve any other organizations in collecting the data? If so, what kinds of organizations were they (and would they like acknowledgment in the final report)?
2. What data-collection methods did you use?
3. When was data collection carried out? (time periods for interviews, visits to facilities)
4. If you carried out interviews, how many NGOs, prevention of perinatal transmission programs (PPT) and health facilities did you interview?
5. What positions did NGO, PPT and health facility staff that you interviewed have (e.g., program managers, directors)?
6. If you carried out observation visits to facilities, how many visits did you make (and to what kinds of facilities, e.g., to see if IEC materials were available)?
7. If you carried out mystery client visits, how many visits did you make (and to what kinds of facilities)?
8. Did any NGOs, PPTs or health facilities refuse to provide data? If so, do you know why?
9. Which documents did you review for the assessment?
10. What difficulties did you encounter in collecting data?
11. Would you change or add questions to any of the benchmarks?
12. Would you be willing to participate in another round of data collection in November 2005?
13. How do you plan to disseminate your local findings and the final overall report prepared by Ipas?
14. Any other comments on the project:

APPENDIX 4: BARCELONA BILL OF RIGHTS

A global effort initiated by Women at Barcelona and Mujeres Adelante with lead involvement by the International Women's AIDS Caucus of the International AIDS Society and the International Community of Women Living with HIV/AIDS

As we enter the third decade of HIV/AIDS, women, especially the young and the poor, are the most affected. Because gender inequality fuels the HIV/AIDS pandemic, it is imperative that women and girls speak out, set priorities for action and lead the global response to the crisis. Therefore, women and girls from around the world unite and urge all governments, organizations, agencies, donors, communities and individuals to make our rights a reality.

Women and girls have the right:

To live with dignity and equality

To bodily integrity

To health and healthcare, including treatment.

To safety, security and freedom from fear of physical and sexual violence throughout their lives

To be free from stigma, discrimination, blame and denial

To their human rights regardless of sexual orientation

To sexual autonomy and sexual pleasure

To equity in their families

To education and information

To economic independence

These fundamental rights shall include, but not be limited to the right:

To support and care which meets their particular needs

To access acceptable, affordable and quality comprehensive healthcare including antiretroviral therapies

To sexual and reproductive health services, including access to safe abortion without coercion

To a broader array of preventive and therapeutic technologies that respond to the needs of all women and girl regardless of age, HIV status or sexual orientation

To access user-friendly and affordable prevention technologies such as female condoms and microbicides with skills building training on negotiation and use

To testing after informed consent and protection of the confidentiality of their status

To choose to disclose their status in circumstances of safety and security without the threat of violence, discrimination or stigma

To live their sexuality in safety and with pleasure irrespective of age, HIV status or sexual orientation

To choose to be mothers and have children irrespective of their HIV status or sexual orientation

To safe and healthy motherhood for all, including the safety and health of their children

To choose marriage, form partnerships or divorce, irrespective of age, HIV status or sexual orientation

To gender equity in education and lifetime education for all

To formal and informal sexual education throughout their lives

To information, especially about HIV/AIDS, with an emphasis on women and girls' special vulnerability due to biological differences, gender roles and inequality

To employment, equal pay, recognition of all forms of work including sex work and compensation for care and support

To economic independence such as to own and inherit property, and to access financial resources

To food security, safe water and shelter

To freedom of movement and travel irrespective of HIV status

To express their religious, cultural and social identities

To associate freely and be leaders within religious, social and cultural institutions

To lead and participate in all aspects of politics, governance, decision-making, policy development and program implementation

XIV International AIDS Conference, Barcelona, Spain, 11 July 2002

APPENDIX 5: CONTACT INFORMATION FOR PROJECT PARTNERS

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