



# “There’s nothing you could do if your rights were being violated”

## Monitoring Millennium Development Goals in relation to HIV-positive women’s rights

**Report on a project by:**

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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
BONELA	Botswana Network on Ethics, Law and HIV/AIDS
BONEPWA	Botswana Network of People Living With HIV and AIDS
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
EC	Emergency contraception
FEIM	Fundación de Estudio e Investigación de la Mujer
FP	Family planning
GAF	Gender AIDS Forum
GIPA	Greater Involvement of People Living with HIV/AIDS
Global Fund	Global Fund to Fight AIDS, Tuberculosis and Malaria
HPV	Human papillomavirus
ICW	International Community of Women Living with HIV/AIDS
IEC	Information, education and communication
IES	Instituto de Educación y Salud
IPPF	International Planned Parenthood Federation
IUD	Intrauterine device
MDG	Millennium Development Goal
MoH	Ministry of Health
NGO	Nongovernmental organization
PAU	Policy Advocacy Unit
PECAC	Punto de Encuentro de la Comunidad, A.C.
PEP	Post-exposure prophylaxis
PHA	People living with HIV/AIDS
PMTCT	Prevention of mother-to-child transmission
PPFN	Planned Parenthood Federation of Nigeria
PPT	Prevention of perinatal transmission of HIV
SRH	Sexual and reproductive health
STI	Sexually transmitted infection
TOP	Termination of pregnancy
UN	United Nations
UNAIDS	The Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Program
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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- 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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# PREFACE

In the year 2000, 189 countries at the United Nations (UN) General Assembly endorsed a Millennium Declaration in which they proposed to make measurable progress toward the development of all nations by the year 2015 [1]. Eight Millennium Development Goals (MDGs) were delineated for achievement of the Declaration. While none of them directly address sexual and reproductive health (SRH) in broad terms, three are especially pertinent to women's reproductive health:

- MDG 3 seeks to promote gender equality and empower women
- MDG 5 aims to improve maternal health
- MDG 6 focuses on combating HIV/AIDS, malaria and other major diseases.

Targets and indicators were developed to help governments mark their progress towards the MDGs, but these targets and indicators are macro-level in scope and thus not so useful for many smaller NGOs that wish to assess interim progress in specific geographical or content areas. For example, the target for MDG 5 is reduction of a country's maternal mortality rate by 75%, and an indicator is the maternal mortality ratio [2]. A smaller NGO that works on maternal health may be more interested in knowing whether their advocacy work on reducing unsafe abortions has had an effect on policies related to HIV/AIDS.

Because the MDGs now form a widely used approach to development, it is important that NGOs be able to situate their advocacy and intervention work in this framework. One way to achieve this is by using benchmarks to assess progress toward achieving the MDGs and their associated targets. It was in this context that Ipas took the lead, in collaboration with ICW, the Center for Health and Gender Equity (CHANGE) and the Pacific Institute for Women's Health, in developing a resource called *Fulfilling reproductive rights for women affected by HIV. A tool for monitoring achievement of Millennium Development Goals* [3]. The monitoring tool suggests benchmarks that can help determine how MDGs 3, 5 and 6 are being met in relation to the SRH of women affected by HIV/AIDS.

In 2005 and 2006, eight organizations partnered with Ipas to pilot the benchmarks as a data-collection method in 11 countries. They included organizations of women living with HIV/AIDS, family-planning associations, and national and local NGOs:

- The Federation for Women and Family Planning (hereafter referred to as the Federation) is a member association of the International Planned Parenthood Federation (IPPF) that works on SRH in Poland [4].
- The Foundation for Studies and Research on Women (FEIM) carries out advocacy and research on SRH in Argentina [5-6].
- GAF is an NGO working on gender and HIV and AIDS issues in South Africa [7].

- The Instituto de Educación y Salud (IES) carries out SRH research and interventions in Peru [8].
- ICW, the only international network exclusively representing HIV-positive women and girls, used the benchmarks in Botswana, Lesotho, Namibia and Swaziland [9–11].
- PPFN, a member association of IPPF, used the benchmarks in data collection in the North–East region of the country [12].
- Punto de Encuentro de la Comunidad, A.C. (PECAC) is the only NGO working on HIV/AIDS in Chetumal, the state capital of Quintana Roo, Mexico [13].
- Women Fighting AIDS in Kenya (WOFAK) is an association that provides counseling, training and material support to women living with and affected by HIV/AIDS [14].

The Federation, FEIM, GAF, ICW in Lesotho and Swaziland, PECAC and WOFAK participated in the first phase of the project in 2005; FEIM, ICW in Botswana and Namibia, IES and PPFN carried out projects in the second phase during 2006. Each partner prepared its own project report and disseminated its findings independently. Ipas collated the findings from the various studies and updated the monitoring tool to address suggestions for improvements given by the partners [15].

In 2005, Ipas produced a report with a detailed description of the rationale, methodologies and overall findings from the first phase of the project [16]. Since the methodologies in the second phase largely replicated those used originally, this report does not provide extensive information in that regard; readers are referred to the first report or the individual country reports for details. This report combines the findings from the first and second phases of the project, so some duplication of text from the first report has occurred. This report is further somewhat unconventional in that the recommendations emerging from the project — which are usually presented at the conclusion of a paper — are given at the start since that information may be what interests readers most.

# RECOMMENDATIONS FROM THE PROJECT

The findings from the MDG–SRH–HIV monitoring tool project indicate that a number of obstacles at the national and local levels are hindering achievement of the MDGs on advancing gender equality and the empowerment of women (MDG 3), improving maternal health (MDG 5) and combating HIV/AIDS (MDG 6). Addressing some of these obstacles requires substantial financial and human resources; others can be tackled to at least some extent with fewer inputs by both governmental and nongovernmental organizations working on HIV/AIDS. The recommendations below are based on suggestions from study respondents and staff of partner organizations in the project.

## **Disseminate practical information on human–rights standards and ways in which women can claim their rights**

People affected by and living with HIV, service and health–care providers, NGO staff and policymakers need to be better informed about human rights, including sexual and reproductive rights, in the context of HIV/AIDS.

Disseminating documents such as IPPF’s summary guide to sexual and reproductive rights [17], the Barcelona Bill of Rights [18] and the International Guidelines on HIV/AIDS and Human Rights [19] — 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 voluntary HIV counseling and testing (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 know which international rights treaties their government has ratified, lobby for ratification of relevant treaties that have not yet been ratified, understand how rights guaranteed in treaties can be claimed through laws and regulations, and know 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 on how to present cases to ethics committees of hospitals and professional medical associations, how to submit cases for follow–up with local human–rights commissions and ombudspersons, 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 local and national individuals and institutions that should accept complaints about human-rights violations so that they actually deal with those cases in a timely fashion.

Information about these measures can be disseminated through articles in newsletters and journals, brochures and leaflets, radio and TV programs, the Internet 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.

### **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 also have rights regarding their labor situation. For example, they should 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 post-exposure prophylaxis (PEP) available to providers.

It is important to build a stronger rapport between health-care providers and women living with HIV, so that there is more mutual understanding and information in both groups about the particular circumstances and challenges they each face. Training sessions and workshops on the ethics of service provision to people living with HIV/AIDS 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, which educates them about antiretroviral drugs (ARVs) and other medications,<sup>1</sup> can help explain why it is important for patients to be partners with health professionals in treatment implementation.

### **Promote capacity- 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 who could contribute invaluable information to inform and direct policies and programs, have had no formal training on translating their experience into advocacy and action.

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<sup>1</sup> Treatment literacy training covers issues such as types of drugs available, drug dosages, how to take drugs (for example, with or without food), side effects, possible drug interactions, the consequences of nonadherence to treatment regimens, and drug resistance.

The project 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 they can contribute greatly to enhancing women's skills. In addition to offering HIV-positive and affected women training courses and workshops on advocacy and policymaking, another approach to explore is mentoring. 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. Professional policy analysts and researchers can mentor and guide female NGO staff and HIV-positive 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 co-facilitate such capacity-building would be a step in the right direction.

### **Work with associations of HIV-positive women and women's groups specifically to develop advocacy around broader sexual and reproductive health rights**

Much of the advocacy carried out by associations of people living with HIV/AIDS in recent years has focused on issues other than sexual and reproductive rights. Particular attention has gone toward expanding pregnant women's access to antiretroviral therapy (ART) during pregnancy to prevent perinatal transmission (PPT)<sup>2</sup> and expanding access to ARVs. In some countries, advocacy is now shifting somewhat more to improving the circumstances in which ART is offered (for example, via treatment literacy programs, access to better nutrition, lowering or abandoning fees for peripheral services such as CD4 counts and viral load assessments). In most countries, however, reproductive rights are not a priority, particularly where associations of people living with HIV/AIDS are primarily led by or comprise men.

It is nevertheless important for women to have access to other SRH services that will protect and improve their health. Since PEP can be effective in preventing HIV infection after unprotected sex, women need to be informed about this, PEP supplies must be

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<sup>2</sup> 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.

made available, and barriers to accessing PEP should be removed (for example, requirements for having officially reported a rape to the police before being granted PEP).

Given high levels of sexual and domestic violence in all countries, women should have easy access not only to PEP but also emergency contraception (EC) to prevent unwanted pregnancies. Unsafe abortions may particularly pose grave risks to the health of immunocompromised women, so advocacy to increase access to legal abortions should also be undertaken, including in cases of rape and incest, fetal malformations and danger to a woman's physical and mental health. At the same time, advocates can promote incorporation of postabortion care into HIV/AIDS programs, as well as messaging on the fact that pressuring women to undergo sterilization and abortions is a violation of their human rights. Many HIV-positive women are further unaware of their increased risks for cervical cancer and the associated importance of Pap smears and screening for human papillomavirus (HPV).

In all these cases, advocacy efforts can involve four strategies: provision of information and education to women, health-care providers and policymakers on the issues; lobbying for adequate legal and regulatory provisions to enable these aspects of reproductive-health care to be offered; training of HIV-positive women so that they can demand appropriate services; and training and equipping of health-care providers so that they can offer high-quality services.

### **Employ women living with HIV in prevention, VCT and treatment programs as paid counselors and treatment adherence advisers**

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 so that motivational messaging can be improved.

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.

Associations of people living with HIV/AIDS are increasingly offering treatment literacy programs so that HIV-positive people are better informed about all aspects of their medical treatment. Some graduates of these programs could be trained and paid to act as advisers on treatment adherence, particularly for people who live far from ART distribution sites. For example, in Botswana, women living with HIV are asked to collect ART supplies monthly but only have check-ups for side effects every three or six months. To cut time and transportation costs for patients, the health system might consider offering quarterly ART supplies and referrals to community-based treatment monitors who can refer women when they do need to see a physician because of side effects. In countries where the health system has lost many professional staff due to AIDS and labor emigration, such HIV-positive treatment advisers could also assist in local clinic distribution and education on ARVs.

### **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 advisable for women living with HIV to be informed about the double protection against reinfection and pregnancy offered by male and female condoms, they also should receive 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, ARVs and drugs for opportunistic infections. Options for avoiding unwanted pregnancies should also be addressed, including EC and safe abortion for indications permitted by law 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 termination of pregnancy (TOP) is allowed in cases of rape or when a woman's health is endangered. While such materials should be developed through collaboration between governmental AIDS and SRH agencies and family-planning organizations, other NGOs can also play a role.

### **Advocate for the possibility of HIV-positive people adopting children**

While women living with HIV can reduce the chances of perinatal HIV transmission by participating in PPT programs, they can also avoid the risk of perinatal transmission by intentionally preventing pregnancy. Many HIV-positive women, particularly younger women, do indeed want to become pregnant and bear biological children. However, some women and men are interested in adopting children and this option should be possible.

Organizations working on AIDS should ascertain whether legal and regulatory 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/AIDS 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 SRH materials for people affected by HIV. Associations of HIV-positive people can also disseminate stories about successful adoptions through newsletters, websites and conferences; cases from one country can serve as examples and inspiration for people in other countries.

### **Advocate for regular monitoring of SRH benchmarks by female NGO staff and women affected by the HIV/AIDS epidemic**

The monitoring tool project showed that provision of benchmarks, together with some very simple guidance on implementing a data-collection exercise, was sufficient to enable NGO partners in very different countries to collect information on the same topics. By repeating the exercise periodically, NGOs can monitor progress toward achieving fulfillment of women's sexual and reproductive rights, thereby gaining valuable input for their advocacy efforts and enabling them to make even more substantive contributions to policy formulation and evaluation.

From a gender perspective, it is important that NGOs assign female staff members to such exercises, including presentation of results at various venues. It is still not uncommon for women to be more involved in administrative and support tasks related to data collection, rather than in conceptualization and implementation of studies. The insights these women can bring to studies are invaluable. Enabling them to publicly present the findings and recommendations at meetings, press conferences and technical consultations will increase the visibility and recognition of women's contributions to increasing the knowledge base concerning the epidemic and its effects.

***"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" [20].***

It is equally important 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 monitoring tool studies in Botswana, Kenya, Lesotho, Namibia, South Africa and Swaziland, 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.

# 1. INTRODUCTION

## 1.1. BACKGROUND TO THE PROJECT

### Origin of the project

On 8 March 2004, 25 NGOs submitted a statement to the UN Commission on the Status of Women to draw attention to areas of reproductive health that are neglected with regard to HIV-positive women, such as fertility regulation and gynecological care [21]. The benchmarks in this monitoring tool emerged from that statement and were related to the MDGs, which had become a major framework for development work and assistance at the international and national levels.

A gender scan of several national MDG reports by UNDP in 2005 found that most reports did not adequately include gender concerns across all the goals; moreover, “attempts to ‘step out of the box’ and place discussions on issues such as poverty and HIV/AIDS in the larger context of gender equality and women’s rights and freedoms, were infrequent exceptions” [22]. There is no specific SRH goal or target in the MDGs, although UN Secretary General Kofi Annan stated that ensuring access to SRH services promotes development since it advances gender equity and empowers women [23]. 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 [24]. 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 [25–27].

### The logistics

Ipas conceptualized the monitoring tool project and recruited NGOs to participate through personal contacts. The partner organizations approached in the Asian region unfortunately were either unable to participate or could not complete the project work.

The overall project coordinator at Ipas provided sample questionnaires for interviews or surveys, a sample informed consent form for respondents, and ideas for possible data-collection methods. She also reviewed adapted questionnaires prepared by the partner organizations, as well as focus-group guides developed by some partners. Each partner agreed to provide a narrative and financial report on their study, including information on obstacles they encountered in trying out the tool and suggestions on how the monitoring tool could be improved.

Ipas paid each partner US\$2,000 (in 2005) or US\$2,500 (in 2006) to help cover staff time, transportation, photocopying, postage and other logistical costs for the project.

Each organization was asked to gather information related to the following 10 benchmarks:

### **MDG 3: Promoting gender equality and empowering women**

- All relevant local governmental agencies and NGO programs serving HIV-positive women include representatives of these women in policy and program design, monitoring and evaluation.
- All agencies serving local HIV-positive women publicly endorse documents listing their sexual and reproductive rights.

### **MDG 5: Improving maternal health**

- All HIV-positive women have access to family-planning information that addresses contraception in relation to HIV/AIDS.
- Women's choices on how to regulate their fertility do not prevent them from accessing ART.
- Information is available to people living with HIV about methods to improve the safety of conception and childbirth.
- HIV-positive women and men are informed about all their legal options for parenting children.
- Local organizations serving HIV-positive women address all legal options for dealing with unwanted pregnancy.

### **MDG 6: Combating HIV/AIDS**

- VCT is available to women through health-care facilities other than antenatal and delivery care, as well as other venues.
- Measures have been taken to minimize chances of HIV infection for women who have been subjected to coerced or forced sex, both within and outside marriage.
- Stigma and discrimination in relation to HIV/AIDS have been successfully eradicated in the health-care sector.

### **Data-collection processes**

Most of the partner organizations had staff members (including women living with HIV in Botswana, Kenya, Lesotho, Namibia, South Africa and Swaziland) conduct the studies. The Federation, FEIM, GAF and PPFN also included consultants in their teams. The studies in Argentina's Buenos Aires province, Kenya, Lesotho, Mexico, Poland, South Africa and Swaziland were carried out from January-May 2005. The studies in other Argentinean cities, Botswana, Namibia, Nigeria and Peru were done from January-May 2006.

All project partners used questionnaires based on the sample questions provided (Table 1, p. 15). The questions were answered in various ways. For example, in Nigeria, respondents completed the surveys in writing, in Argentina and Kenya interviewers read

out the questions and recorded responses, and in Botswana the questions were read out to a group of women who discussed what the best answers would be. Interviews generally lasted between 40–90 minutes; for the policymakers and staff of NGOs and health facilities, the interviews mostly took place at their places of work.

GAF, ICW, IES, PPFN and WOFAK also organized focus–group discussions with respondents, which generally lasted about 60–90 minutes. All the discussions were held in English or Spanish (Peru), with the exception of one group in Nigeria that spoke Hausa and three groups in Namibia that held their discussions in a local language. The groups sometimes discussed other topics in addition to those covered by the benchmarks. For example, in Kenya, the main concern expressed by HIV–positive 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. HIV–positive widows’ main concerns were related to property ownership, inheritance rights and protecting their daughters against HIV infection. 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.

Three partners included site visits in their studies. In Mexico, PECAC interviewed staff of six pharmacies about the sale of EC. PECAC and PPFN in Nigeria collected samples of information, education and communication (IEC) materials available at specific sites in each country (e.g., brochures and posters dealing with HIV/AIDS, family planning, contraceptive measures and human rights). In Poland, the Federation visited a hospital, two diagnostic centers and five NGOs in Warsaw.

Most partners provided their respondents with the Barcelona Bill of Rights [18], a policy statement formulated in 2002 by HIV–positive women’s associations and endorsed by more than 260 individuals and organizations worldwide. All the partner organizations reviewed documentation related to HIV/AIDS policies, laws, regulations and programs within their countries.

The categories of respondents included in the various studies comprised representatives of governmental agencies at the municipal, state and national levels; staff of NGOs and associations of people living with HIV/AIDS; health–care providers; heads of clinic and hospital programs and departments; and individual men and women living with HIV (Table 2, p. 16). The NGOs included family planning associations, AIDS service organizations, feminist groups and human–rights agencies.

Two of the partners used the studies as an opportunity for awareness–raising and capacity–building. In Lesotho and Swaziland, ICW reviewed human–rights documents with their respondents, including the Barcelona Bill of Rights [18], the UNGASS

Declaration of Commitment [28], the Abuja Declaration [29] and the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) [30].

For GAF, the research process was as important as the information obtained; their project was somewhat time-consuming and more complicated than the other projects. Their eight-step research process included a training workshop for the research teams that covered: definitions of research from knowledge-systems and feminist perspectives, research principles, data-collection and analysis techniques, an introduction to the MDGs, and a review of international human-rights instruments. ICW incorporated the monitoring tool study into ongoing projects in Botswana, Lesotho, Namibia and Swaziland; the monitoring tool focus-groups took place within the context of broader skills-building workshops.

## **1.2. GEOGRAPHICAL AND SOCIAL CONTEXT FOR THE STUDIES**

The monitoring tool projects were carried out primarily in very poor countries, where government spending on all health services ranges from US\$13 (Nigeria) to US\$518 (Argentina) per capita. Four projects were carried out in countries with relatively moderate HIV/AIDS epidemics — Argentina, Mexico, Peru and Poland — while seven projects took place in countries with advanced epidemics — Botswana, Kenya, Lesotho, Namibia, Nigeria, 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. Table 3 (p. 17) provides some comparative information on the countries' socioeconomic and HIV/AIDS situations; data from the United States are given for comparison purposes.

ICW was able to gather respondents from throughout Botswana, Lesotho, Namibia and Swaziland since they incorporated the MDG project into national workshops. In Argentina, FEIM focused on cities with high HIV prevalence levels: Buenos Aires and greater Buenos Aires, Bahía Blanca, Córdoba, Mar del Plata and Rosario. WOFAK was able to include respondents in three cities where they have staff — Kisumu, Mombasa and Nairobi. The Federation focused on two larger Polish cities, Warsaw and Szczecin, with relatively high numbers of HIV-positive residents. In South Africa, GAF held five focus groups with women in two areas near Durban and one near the city of Pietermaritzburg, all in the province of KwaZulu Natal which has high HIV prevalence. In Peru, IES restricted data collection to the capital city, Lima, due to funding and time constraints. In Mexico, PECAC focused on Quintana Roo state, while in Nigeria PPFN worked in four states (Bauchi, Borno, Gombe and Yobe) with HIV-positive women and health-facility staff.

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

Project partner	Data-collection method				
	Questionnaire completed by respondents	Questionnaire-based interviews	Focus-group discussions	Document & literature review	Visits/observation
FEIM, Argentina Buenos Aires & Bahía Blanca, 2005		24 persons		Yes	6 hospitals; 3 health-care centers; 5 NGOs
Córdoba, Mar del Plata & Rosario, 2006		29 persons		Yes	
ICW, Botswana, 2006 National workshop	14 persons		1 group: 14 members	Yes	
WOFAK, Kenya, 2005 Kisumu, Mombasa & Nairobi	43 persons		3 groups: 10 HIV-positive widows; 10 HIV-positive men; 10 HIV-positive women < 30 years		
ICW, Lesotho, 2005	14 persons		1 group: 11 members	Yes	
PECAC, Mexico, 2005 Chetumal, Quintana Roo state		27 persons		Yes	12 facilities; 6 pharmacies
ICW Namibia. 2006 Erongo & Khomas regions	6 persons (3 women, 3 providers)	6 persons (same as in column 1)	4 groups: 69 members		
PPFN, Nigeria, 2006 Bauchi, Borno, Gombe & Yobe states	94 persons (54 women, 40 NGO & health staff)		2 groups: 21 women	Yes	4 family planning clinics; 5 NGOs; 6 hospitals
IES, Peru, 2006		12 persons	6 groups: 58 members	Yes	
Federation, Poland, 2005 Warsaw and Szczecin		8 persons		Yes	1 hospital; 2 diagnostic sites; 5 NGOs
GAF, South Africa, 2005 KwaZulu Natal (Pietermaritzburg & Durban areas)		20 persons	5 groups		
ICW, Swaziland, 2005	20 persons		1 group: 7 persons	Yes	

**Table 2: Types of respondents approached by the project partners. \*The persons identified as HIV-positive in the projects carried out by FEIM and the Federation also represented NGOs. PHA = people living with HIV/AIDS.**

Project partner	Type of respondents (No.)				
	HIV-positive women & men	NGO directors/staff*	Clinic & hospital staff	Other health facilities	Governmental program staff
FEIM, Argentina Buenos Aires & Bahía Blanca	6 persons (3 PHA groups)	8 persons (3 PHA groups & 5 NGOs)	7 persons (7 service facilities)		5 persons (2 national. 1 provincial & 2 municipal programs)
Córdoba, Mar del Plata & Rosario	3 women (one for PHA group)	10 persons (9 NGOs)	7 persons (3 hospitals)		9 persons (3 provincial & 6 municipal programs)
ICW, Botswana	14 women				
WOFAK, Kenya	36 persons	4 persons (3 NGOs, 1 PHA association)	2 persons (2 hospitals)		1 person (Ministry of Education)
ICW, Lesotho	14 women				
PECAC, Mexico	3 women		10 persons (3 hospitals, 1 clinic, 1 urban health center)	8 persons (2 state-level facilities, blood bank, medical association, laboratory) 6 pharmacy staff	6 persons (including programs on population, women, adolescents, human rights)
ICW, Namibia	72 women	2 persons (2 NGOs)			1 person (Ministry of Health)
PPFN, Nigeria	75 women	5 persons (5 NGOs)	6 persons (6 hospitals)	4 persons (4 family planning clinics )	
IES, Peru	58 women	4 persons (2 NGOs)			8 persons (4 national & 4 provincial 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, Swaziland	20 women				

**Table 3: Information on some socioeconomic and HIV/AIDS data for the project countries compared with data for the United States (source [31] except \*, which comes from [32]); – means no data provided.**

Country	Per capita gross national income (US\$)	Per capita government spending on health (US\$)	Persons living on <US\$ 2/day (%)	HIV prevalence (15–49 years; %) No. of HIV-positive women (15 years & older)	HIV-positive persons receiving ART (%)	Pregnant women receiving ART for PPT (%)
Argentina	12,460	518	14.3	0.6 36,000	81.0	87.0
Botswana	8,920	218	50.1	24.1 140,000	85.0	70–79*
Kenya	1,050	25	58.3	6.1 740,000	19.7	9.3
Lesotho	3,210	84	56.1	23.2 150,000	14.0	5.1
Mexico	9,590	270	26.3	0.3 42,000	71.0	2.1
Namibia	6,960	252	55.8	19.6 130,000	35.0	25.0
Nigeria	930	13	90.8	3.9 1,600,000	7.0	0.2
Peru	5,370	112	37.7	0.6 26,000	52.0	3.5
Poland	1,240	521	–	0.1 7,500	100	–
South Africa	10,960	258	34.1	18.8 3,100,000	21.0	14.6
Swaziland	4,970	185	–	33.4 120,000	11.9	31.0
USA	39,710	2548	–	0.6 300 000	70.1	–

Despite the differences in the level of their epidemics, the project countries are similar in that many of their female residents find their decisionmaking capacity in the domestic and public spheres restricted by gender-based societal norms. For example, a review of MDG reports from a gender perspective found that adolescent mothers in Botswana cannot overrule their husbands and exercise choices in general, while in Kenya women are unable to negotiate safer sex due to their low social status, which also contributes to infant mortality [22].

Domestic violence and sexual violence against women are major public–health problems in all 11 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 [33]. South Africa has one of the highest rates of rape in the world, with the Law Commission estimating 1.6 million occurrences annually [34]. Indeed, UN Secretary General Annan recently recommended that national governments and donors immediately increase and sustain funding “to address gender inequalities that fuel the epidemic among women and girls, reform and enforce legislation, where needed, to protect women and girls from harmful traditional practices and from sexual violence in and outside marriage and ensure equality in domestic relations...” as part of an effective worldwide response to the AIDS pandemic [35].

The projects in Argentina, Peru and Poland particularly noted that there are few links between HIV/AIDS and reproductive–health programs and services. This disconnect is found at all levels, ranging from national programs to hospitals and clinics. The Rosario municipal AIDS program in Argentina did disseminate a folder on gender and HIV/AIDS that advocated for the right of HIV–positive women to decide whether they want children. However, a respondent in the Buenos Aires province commented: “... in practice, no one has assumed responsibility for addressing contraception for people with HIV. ... 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.’” In Peru, representatives of the National Health Strategy for Sexual and Reproductive Health said that issues related to women and HIV are not their concern but should be handled by the National HIV/Sexually Transmitted Infections (STI) Health Strategy. Respondents in Swaziland commented that there are no SRH services for women living with disabilities and that, due to customary practices related to the death of a spouse, widows find it hard to access all kinds of health care.

Not all the project partners were able to ascertain adoption agencies’ policies regarding the HIV status of potential adoptive parents. In the African countries, respondents in any event tended to think in terms of informal adoption of grandchildren, nieces and nephews since many families are already caring for children orphaned due to AIDS.

The abortion laws in the countries vary. A large number of respondents in all countries spoke about abortion being illegal, and they did not know the indications for which pregnancy may be legally terminated (or they considered it too difficult to obtain legal abortions). The indications for which abortion is permitted by law are:

- Argentina: when pregnancy poses danger to a woman’s health or life or when a mentally disabled woman becomes pregnant due to rape [36]
- Botswana: rape and incest; risk to the life of the pregnant woman or injury to her physical or mental health; if the child were born, it would suffer from or later develop such serious physical or mental abnormality or disease as to be seriously handicapped [37]
- Kenya: when pregnancy endangers a woman’s life [38]
- Lesotho: when pregnancy endangers a woman’s life [39]

- Mexico, Quintana Roo state: to save a woman's life; in cases of pregnancy due to rape and in cases of fetal malformation [40]
- Namibia: in cases of danger to a woman's life; serious threat to her physical or mental health; a serious risk that the child to be born will suffer from a physical or mental defect of such a nature that he will be irreparably seriously handicapped; rape; or illegitimate intercourse with a woman who is permanently mentally disabled [41]
- Nigeria: to save a woman's life [42]
- Peru: in cases of extramarital rape; unlawful artificial insemination outside marriage; and grave mental or physical handicaps of the fetus [43]
- Poland: severe danger to a woman's health [44]
- South Africa: 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 [45]
- Swaziland: to save a woman's life [46].

## Country-specific background information

**Argentina.**<sup>3</sup> About 65% of HIV infections are found in the country's capital, Buenos Aires, and its immediate surroundings. Since 1997, the government has mandated that pregnant women must be offered an HIV test and ART for PPT if the woman is found to be HIV-positive [47]. Replacement feeding is made available through the public health system for children up to two years of age [48]. Most HIV-positive people 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 [49]. 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 [49].

Nevertheless, some people have difficulty obtaining 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. There are no special HIV-prevention services for women and girls, and the National AIDS Program has no agencies or bodies specifically focused on women's issues [48]. There are numerous self-help groups for HIV-positive people, and the ICW Latin American coordinator is in Argentina.

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<sup>3</sup> Where no references are cited, the information provided comes from the project partners' reports.

**Botswana:** The country's severe AIDS epidemic has caused life expectancy to fall nearly 30 years since 1995, to 37 years for men and 36 years for women. The government now mandates routine opt-out HIV testing at health facilities throughout the country. Between 2001–2005, HIV prevalence among pregnant women remained at 34–37% [50].

ART for PPT is offered at all public health facilities and uptake was estimated at 60.3% in 2004 [50]. While high numbers of HIV-positive people have access to ART through 32 government, mission and mine hospitals [51] and infant formula is provided free of charge, the health infrastructure is straining to provide services. The country lost approximately 17% of its health-care workers due to AIDS from 1999–2005 [50] and many health-care providers are seeking employment in other countries. HIV-positive women may have to travel up to 200 km to reach a hospital where they will receive a monthly supply of ART, whereas they only receive check-ups for side effects every three or six months. Only one hospital offers pediatric formulations of ARVs [52]. In addition to the Botswana Network of People Living With and Affected by HIV and AIDS (BONEPWA), a women's support network, Bomme Isago Association, was formed in 2006. ICW is collaborating with a project called Parliamentarians for Women's Health, which focuses on work with five parliamentarians to build awareness of women's health issues, with a particular emphasis on HIV-positive women's health rights and concerns, and to build the capacity of parliamentarians to influence policy in this area.

**Kenya:** Community-based research found that the Kenyan government's endorsement of the 2001 UNGASS Declaration of Commitment on HIV/AIDS had no evident impact on women's and girls' vulnerability to HIV [31]. The gender difference in HIV infection rates is most pronounced among young people; prevalence among young women aged 15 to 24 years in 2004 was 4.9% compared to 0.9% for their male counterparts [53]. 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 [54]. Research also showed that between 2002 and 2004, HIV-positive men were twice more likely to be admitted to hospital than HIV-positive women; moreover, the women paid 65% more per visit than the men. Female life expectancy has dropped below that of men due to AIDS [31]. In 2005, all provincial and 70 district hospitals, as well as some NGOs, were providing ART free of charge but patients may have to pay fees for viral load tests or CD4 counts; 759 facilities were offering ART for PPT with uptake by 60% and 58% of mothers and infants, respectively [53]. Four Family Planning Association of Kenya clinics are now offering ART through a service model offering comprehensive SRH care [31]. Large numbers of NGOs and associations of HIV-positive people are working on HIV/AIDS issues; about 40% of health care is provided through Christian health associations.

**Lesotho:** Surveys have shown that up to two-thirds of young women aged 15 to 24 years cannot name three HIV prevention methods [54]; this undoubtedly contributes to the high rate of HIV prevalence among antenatal clinic attenders, which was about 27% in 2004 [31]. The country initiated a "Know your status" program in 2005, in which 3,000 community health workers are to be trained to go door to door to encourage all citizens to have an HIV test [31]. However, the government only allocated 3,000 maloti (US\$ 465) to support post-test referrals

and services [55]. About 40% of health-care services in the country are provided by Christian health services [31]. At the end of 2005, about 8400 people were receiving ART, while it was estimated that 58,000 need such treatment [32].

**Mexico:** 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 [54]. Quintana Roo is one of the states with the highest HIV prevalence in Mexico; in 2003, the rate was 0.55% [56]. The federal government reports that there is universal access to ART for HIV-positive persons (provided by 171 public health sector facilities as of 2003), but not to all drugs needed to treat opportunistic infections; moreover, there are sometimes problems with ARV supplies [57]. The government has also affirmed a need to operationalize policies guaranteeing that HIV-positive women, sex workers and transgender women receive health-care services free of stigma and discrimination [57]. The number of NGOs working on AIDS issues is much higher in the capital city than other places; PECAC is one of only a very few civil society organizations addressing HIV/AIDS in Quintana Roo state.

**Namibia:** By 2006, 143 community counselors had been trained to offer VCT at 43 health facilities in the country [58]. HIV prevalence among antenatal clinic attenders is quite high in some cities, ranging from 22–28% in some port cities to more than 42% in an area bordered by Angola, Botswana and Zambia [31]. Eighty-eight percent of hospitals, health centers and clinics are run by the government. Thirty sites offered ART by the end of 2005; 34 hospitals and 79 general health clinics offered ART for PPT [58]. Coverage is uneven throughout the country, however, as some districts and regions have low numbers of physicians, pharmacists and pharmacist assistants. As in Botswana, ICW in Namibia is collaborating on the Parliamentarians for Women's Health project.

**Nigeria:** By the end of 2005, there were 228 sites offering VCT throughout the country [59]. Although Nigeria has a relatively low HIV prevalence rate, it is the most populous African nation and has the third-largest number of HIV-positive residents in the world [31]. HIV prevalence ranges from 2.0–3.9% in Borno and Yobe states and 4.0–5.9% in Bauchi state to 6.0–7.9% in Gombe state [60]. About 50 sites provide ART throughout the country; 33 are government-run and 17 offer services through NGOs, the private sector and faith-based organizations [60]. Many of these sites are in urban centers, requiring rural people to spend considerable sums on transportation and lodging to gain access to free or low-cost treatments. Some 1300 AIDS-specific and other civil society organizations work on HIV/AIDS issues, including some 300 self-help groups involved primarily in care and support [59].

**Peru:** Thus far, the HIV epidemic in Peru has been largely concentrated among men who have sex with men; rates among female sex workers, for example, have remained relatively low [31]. Nevertheless, the number of women infected with HIV has increased over time. About 31% of pregnant women have been reached with VCT during antenatal care; of those diagnosed HIV-positive, only 37.4–47.4% received ART for PPT from 2002–2004 [61]. The majority of poor

people living with HIV receive health services through the public sector, which has some 220 hospitals concentrated in six of 25 departments. The system also runs health centers and health posts, which are more widely distributed but do not offer all kinds of health services. Associations of people living with HIV/AIDS have been quite active in the country for some years and collaborate with other NGOs and civil society organizations through networks.

***Poland:*** The country has 17 testing centers in the larger municipalities [62]. Most new registered cases of HIV infection in Central Europe are found in Poland; since 1985, more than half of those infections have been associated with drug use [31]. 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 than men [63]. 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 interview information gathered from doctors who provide care to HIV-positive mothers and their children, it is estimated that about 200 to 220 HIV-positive women give birth every year. In 2001, 23 women known to be HIV-positive received ongoing antenatal care; 19 of them received ART to prevent perinatal transmission [64]. By October 2005, 14 reference clinics and penitentiary centers were providing ART [62]; these included the National AIDS Center, Regional Sanitary-Epidemiological Stations and the Center for AIDS Diagnostics and Therapy. NGOs play an important role in HIV prevention and give support to HIV-positive people throughout the country. The government reports that 59 NGOs have collaborated with the National AIDS Center in recent years [62].

***South Africa:*** In 2004, HIV prevalence among women at public-sector antenatal clinics was highest in KwaZulu Natal at 40.7%; the country average is 29.5% [65]. In a study some years earlier, as many as 40% of abortion clients in KwaZulu Natal tested HIV-positive [66], but more HIV-positive women may be choosing to carry pregnancies to term now that ART is somewhat available. 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 [67]. The 204 sites accredited by the end of 2005 to offer ART include government health facilities, private sector facilities and NGOs; 54 of the sites were in KwaZulu Natal [68]. Civil society has noted that some hospitals equipped to offer ART have not yet been accredited and therefore cannot offer treatment [65]. Some private sector businesses that provide ART through medical insurance believe workers may be underusing treatment services due to stigma [31]. In 2005, 3064 health facilities were offering ART for PPT [68]. A wide variety of NGOs and civil society organizations are active in AIDS-related work in South Africa; there is some tension between them and government about issues such as provision of ART (the Treatment Action Campaign forced the government to roll-out ART for PPT through court actions).

***Swaziland:*** 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 [69]. Among young pregnant women aged 15–24 years, the prevalence rate remained at 39.4% between 2002 and 2004 [70]. In 2005, 17 health facilities in the country were offering ART but client follow-up has proved to be of concern. By September 2005, 44 sites were offering ART for PPT and 52% of pregnant women were accepting this offered treatment [70].

## 2. KEY PROJECT FINDINGS

Ultimately, not all the project partners collected information on all 10 benchmarks specified in the project description. In Kenya, for example, little information was gathered specifically on stigma and discrimination, while GAF did not collect much information on PEP. The key findings in the 11 countries related to the assessed benchmarks are presented below in six main categories:

- 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
- Fertility regulation, including access to contraceptive information in the context of HIV/AIDS, access to a range of contraceptives, childbearing and infant feeding, availability of EC, and availability of safe abortion services
- Parenting options for persons living with HIV, including assisted conception (such as sperm washing and in-vitro fertilization) and legal adoption
- The availability of VCT and PEP to help women prevent HIV transmission
- HIV/AIDS-related stigma and discrimination within the health-care sector.

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

#### Premise

One basic premise underlying the benchmarks is that awareness of sexual and reproductive rights is essential for achieving the MDGs and for providing HIV-positive women with comprehensive health care. The right to health has been established in the constitutions or laws of countries around the world. International human-rights conventions have further established that all people have a right to health and health care. All UN member states have endorsed at least one human-rights treaty that refers to the right to health and/or health care; therefore their governments are obliged to respect, protect and fulfill the ability of all people to have equitable access to needed health-care services.

The right to reproductive health has also been cited as critical to achieving the MDGs. The UN Secretary General noted that: “Confronting the epidemic requires a stronger integrated response to AIDS, tuberculosis and other diseases, stronger primary health care, stronger maternal health care, stronger sexual and reproductive health programmes and stronger paediatric care” [35]. African Union state leaders concluded that 100% access to SRH services is needed [71] and all states endorsing the political declaration from the 2006 UN General Assembly High-level Meeting on AIDS reaffirmed the goal of achieving universal access to

reproductive health by 2015, as well as health care and services related to SRH for women and girls [72].

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. For HIV-positive people, fulfillment of this right means they should be enabled to decide what kind of available treatment to receive after being fully informed about the benefits and drawbacks of various options. With the advent of ART, an increasing number of associations of HIV-positive people are carrying out treatment literacy projects, often with some support from UN agencies such as the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO).

Women and health-care providers also need to know that violations of women's sexual and reproductive rights can be reported so that persons who are denied proper care can seek fulfillment of their rights through national and international legal systems. Ideally, they will be familiar with international and national documents that explain sexual and reproductive rights, such as the Barcelona Bill of Rights [18] 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 [19].

## Findings

Familiarity with the Barcelona Bill of Rights was limited in all of the project countries, with the exception of Kenya, where 22 of 36 women living with HIV said they were familiar with it; nine women had a copy of the document. In Lesotho, one woman reported familiarity with the preamble to the Universal Declaration of Human Rights and three women mentioned that they were aware of organizations with a rights-based mission (Women in Law in Southern Africa and FIDA, an association of women lawyers). The focus-group participants in Nigeria said they knew of conventions and declarations that guarantee their rights, with one woman remarking: "When I attended a national workshop, I became envious and collected many policies on reproductive health and declarations for our use and photocopied them and distributed them to our members." In contrast, 87.5% of the 54 women who completed a questionnaire in Nigeria said they were unfamiliar with human-rights documents, which might indicate that the focus-group participants were more active in organizations that advocate for rights.

Though some health-care providers in most countries said they knew of 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.

In Peru, review of the National SRH strategy revealed one reference to sexual and reproductive rights for women in general; the National HIV/STI strategy only mentions HIV-positive women

specifically when referring to PPT and interventions with sex workers. All the studies indicated that while national government programs and hospital regulations may endorse women's rights in public, 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. In Argentina, for example, both government and NGO respondents stated that respect for rights varies between and within services, depending on the staff on duty. They stressed that rights will not be guaranteed without training of health-service providers.

Members of the focus-group discussion with widows in Kenya remarked that they wanted law reforms that would create a supportive environment for HIV-positive women to claim their rights. The younger HIV-positive focus-group members said they are denied sexual and reproductive rights; they 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.

Two women in Swaziland reported that their groups or organizations promote reproductive rights for women living with HIV/AIDS, one 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."

The large majority of respondents in all countries except Peru were interested in receiving more information about rights. Most respondents expressed interest in the Barcelona Bill of Rights and most institutional representatives were willing to display or otherwise make it available for their clients. In Mexico, the representative of a local human-rights agency said they would include the Bill in training courses and disseminate it as a brochure or leaflet. In Peru, comments were made that the Barcelona Bill of Rights would not be useful because it has not been endorsed by States and therefore does not carry governmental obligations as do treaties and laws. However, representatives of feminist organizations agreed that sexual and reproductive rights need to be addressed in relation to HIV-positive women; as one said: "At one point, we received many comments and criticisms from HIV-positive female activists in these organizations; they said that nowadays so-called feminists are broaching the topic because it has economic benefits for them. Yes, I think there is an outstanding obligation towards women living with HIV."

**Addressing rights violations:** Many health-care providers and women living with HIV/AIDS did not seem to have a clear idea about how human-rights documents could be relevant to their work environments and daily lives. In Botswana, the women were only aware of the 1995 Beijing Platform for Action [73] and the 2001 UNGASS Declaration of Commitment

[28] as international policy instruments that upheld their sexual and reproductive rights. They did not think that these instruments had been translated into national policy or law and therefore believed recourse was impossible if these rights are violated: There's nothing you could do if your rights were being violated — I'd go back home and sit down." Similarly, a woman in Nigeria said: "It is difficult to claim such a right unless we leave it to the Almighty God."

Nevertheless, respondents did discuss rights violations. In Mexico, representatives of two hospitals knew of at least four and six cases, respectively, that had been reported and handled within their institutions. (Interestingly, 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. As PECAC was concluding its project, it came to their attention that an HIV-positive woman whom they had interviewed was prepared to officially file a case of HIV-related stigma and discrimination with the local Human Rights Commission. The woman had endured harassment from a gynecologist at a hospital for "daring" to get pregnant. She ultimately withdrew the complaint, however, because the Commission said they could not discuss the case anonymously with the hospital and she feared negative repercussions since she relied on that institution for her care and treatment.

NGO representatives interviewed in 2006 in Argentina said that cases of discrimination are not denounced: "The situation of having no defense is such that it is impossible to make a denunciation in the place where you are; it is a situation of dependency on the physician and the whole health team." In South Africa, 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 for women who suffer discrimination is that few of them feel able to challenge health workers, who occupy a position of power; there is always fear of the consequences for their future access to care at the health facility in question. In addition, sustaining participation in a complaints process is often time-consuming, stressful and costly in terms of transport, time, and so on.

One focus group in South Africa 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.

The Nigerian focus-group participants suggested women could involve the media, the Ministry of Women's Affairs, civil society organizations and lawyers' groups.

One case was reported in a South African focus group in which a woman living with HIV asked her 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. The focus-group participants reported that nurses tell HIV-positive people that Bactrim® is only given to patients with tuberculosis, not for prophylaxis.

## 2.2. INVOLVEMENT OF HIV-POSITIVE WOMEN IN POLICIES AND PROGRAMS

### Premise

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 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” [74].

Gender-based analyses of efforts to improve SRH have further asserted that women must be enabled to participate in policymaking and other decisionmaking if any success is to be achieved [26]. It follows that women affected by and living with HIV/AIDS must therefore be involved in decisionmaking regarding reproductive-health policies and programs.

### Findings

Respondents in Argentina, Lesotho and Peru commented that government policies to address HIV-positive women’s needs may be lacking or segmented — some HIV-positive women’s needs are addressed in reproductive or maternal health programs and others in HIV/AIDS programs without any coordination taking place. Some needs are not addressed at all. Respondents in Argentina and Peru also noted that many SRH issues are not high on the agenda of HIV-positive advocates since their primary focus has been on increasing access to ART.

None of the respondents in Argentina said that HIV-positive women are currently involved in policy and program formulation and design, with the exception of respondents in Córdoba and Mar del Plata. In Córdoba, HIV-positive people collaborate on participatory workshops and planning of municipal programs, while in Mar del Plata, the network of associations of HIV-positive people helped organize the municipal AIDS program from the start.

In Peru, HIV-positive women only marginally participate in the formulation of reproductive health policies, which are usually written by technical experts. However, since the implementation of a project funded by the Global Fund against AIDS, Tuberculosis and Malaria (Global Fund), both HIV-positive women and men have been able to influence policies and programs related to ART. The project did find that some women preferred to stay in the background rather than take on active advocacy roles because they wanted to keep their HIV status secret so that their children would not be affected by stigma and discrimination: “Men don’t have the same responsibilities as we women....the men who are organized are gay men.”

The other projects indicated that, on the whole, women living with HIV/AIDS are **not** involved in policy and program formulation, design and evaluation at the local or national levels. Some formal mechanisms exist through which women affected by and living with HIV/AIDS are granted a place on decisionmaking bodies, but respondents in most countries indicated that this involvement is often tokenistic. They also asserted that many women lack the skills and back-up support needed to be effective advocates in such bodies. A young woman in Namibia worded it as follows: “How can we fight for ourselves if we do not have the skills? How can we make our voices be heard if we do not build the capacity to be effective activists on our rights?”

**“I was a member of the CCM [Country Coordinating Mechanism] 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.”**

Respondents in Lesotho noted that they are often the only representatives of people living with HIV/AIDS at a meeting or public gathering organized by other organizations. Frequently, they are called at very short notice, without time to gather the opinions or views of their peers. “Representation” may simply mean being present, 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. Similarly, in Swaziland respondents said that the Business Coalition encourages formulation of workplace policies on HIV/AIDS but only asks HIV-positive women to give personal testimonies for documents and programs: “We are called at short notice and do not have time to prepare.” In Namibia, the women felt that they were “paraded as cattle” to share their stories at meetings.

In Botswana, a woman stated that: “We are used like rubber stamps — we are called at the last minute to approve something that has already been drafted.” This was regrettable, they said, since their insights could adapt programs to better meet their needs. For example, a food basket program includes the same components for all HIV-positive persons, whether they are bedridden or still active. The respondents noted that a meal replacement drink might be suitable for very ill people who have trouble eating but that other foodstuffs might be preferable to create a balanced diet for healthier HIV-positive persons. The women also commented, however, that their input might not actually be welcome: “The more you talk about what you know, the more you annoy the service providers, and they are likely to cancel you from the program. They tell you: “You are not here to tell us what to give you.””

In Mexico, some respondents commented that HIV-positive women can suggest ideas or make complaints about services by depositing notes in boxes at some hospitals and clinics; the three women living with HIV did not know about this possibility. One of them said that this survey represented the first time anyone had asked her opinion about the topics discussed. The women living with HIV in Argentina, Lesotho, Poland and Swaziland in particular commented on the corresponding need for capacity-building in this area. A comment from Swaziland: “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.”

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 HIV-positive women, 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. But as one woman in a focus group in Nigeria commented: “It is better to consult us ... rather than design a program with those that are not infected. This is because we, the infected, know how we feel and if anything we can express it better when our input is embedded in programs meant for us.” (It was interesting to note that 33 of 40 NGO staff felt that they did involve HIV-positive people in drawing up policies and programs; the same number said that HIV-positive women are not involved in program monitoring and evaluation.)

In reality, the GIPA principle is interpreted to mean “a greater role for HIV-positive people in delivering services.” For example, in Argentina, 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.” Health-care providers and HIV-positive respondents in that country also said that trained people living with HIV may be better counselors than health professionals.

The women in Botswana commented that their rights were not protected in research projects and trials, but noted that women often volunteered to participate for the sake of minimal incentives such as money and medications. The Swazi women in particular expressed considerable resentment about being “researched” without being involved in the design and implementation of studies, having those studies explained properly or seeing 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 from reinfection.

## 2.3. FERTILITY REGULATION IN THE CONTEXT OF HIV/AIDS

### Premise

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 [75–77]. 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. It is also important that HIV-positive women receive proper care when they do give birth.

### Findings

**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. Access to contraceptive supplies in urban areas is fairly good. Argentina and Poland are exceptions in this case. In Argentina, availability depends on staff at health services and some women are prohibited by their husbands from using contraception. In Poland, there is considerable opposition to distribution of free contraceptives or state funding 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.

Many HIV-positive women in two countries said they did not seek out family-planning services. Women in Peru said that they mostly rely on condoms to avoid infecting their partners, being re-infected or getting pregnant. Most of these women did not see a need for another contraceptive method, although health-care providers commented that they always recommend both condom use and a second contraceptive method to women living with HIV. In Nigeria, the women in the focus groups said they restrict their health-facility visits to the clinics where they receive ARVs: “At the clinic, mostly the doctors do advise us on family planning and we do have access to all the facilities. However, some religious leaders say we should not stop giving birth.”

Even where modern contraceptives are accessible, the range of contraceptive options may be limited and little information appears to be available regarding contraception in the context of HIV infection. Only one physician in Mexico said that her hospital’s guidelines on ARVs contain some relevant information that is conveyed to patients during counseling. In Peru, a few HIV-positive women had heard that ARVs might have interactions with hormonal contraceptives but most women had not been informed about this. Forty-nine of 54 HIV-positive women responding to a questionnaire in Nigeria had received no such information, and 31 of 40 NGO/health-facility staff said they had no IEC materials to address this issue.

In Botswana, women commented that they receive insufficient information. One woman said: “You find that you are on ARVs and you want to go for family planning [FP] — I went for FP and I chose to be given an injection. It didn’t work out — I had heavy bleeding for three months. When I went to the clinic, I was given something to stop the bleeding, but no additional FP counseling. Now I’m just left with condoms and no other FP information. There isn’t any FP counseling about the interaction between contraceptives and ARVs.” In South Africa, respondents said that the 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 and women were unclear about whether women living with HIV need to be injected more often than women who are HIV-negative and, if so, why.<sup>4</sup>

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<sup>4</sup> 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” [78].

Information materials on contraception for HIV-positive people were scarce in the Buenos Aires province in 2005, and both governmental agency and NGO representatives considered this a new theme to be addressed. In Rosario, in 2006, some materials addressed contraception for HIV-positive women; in Córdoba, the Reproductive Health Program was investigating interactions between hormonal contraceptives and other drugs, including ARVs. In Kenya, WOFAK has some materials that offer information on contraceptives in relation to drugs used to treat opportunistic infections.

Overall, the projects in all countries 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 (though respondents in Kenya, Lesotho and Namibia also mentioned the female condom). In Nigeria, it appeared that health-care providers even discourage use of other contraceptives; one woman said: "As an HIV-positive woman, your immune system has already been attacked. So we are not encouraged to use other contraceptives because there are so many side effects ... which will cause a lot of ailment to an HIV-positive woman." Some respondents in Argentina said constant condom use is an especially difficult subject for serodiscordant couples; a few respondents also mentioned that condoms are promoted to prevent HIV transmission or reinfection, not as a contraceptive method. A woman living with HIV there 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.

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. In Lesotho, 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 Namibia suspected that they were being coerced into using injectable contraceptives: "Health workers [are] telling them they can only access the medicine [ARVs] if they consent to be given an injection and they are not told what this injection is."

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 ARVs are contraindicated for pregnant women); the same thing is stipulated in ART regulations in Peru when women are taking drugs that could potentially harm a fetus. The Peruvian regulations also require that women have gynecological examinations, Pap smears and family-planning counseling before beginning highly active antiretroviral therapy.

***Emergency contraception:*** Knowledge of and access to EC is still limited in the geographical areas assessed by the projects. In some cases, there has been active opposition to making EC more widely available (for example, in Argentina, Botswana, Peru and Poland), while

elsewhere bureaucratic and financial factors impede increased availability within the health sector.

One project in Warsaw advocated that every rape victim be offered EC by the police, but they encountered very strong protests against this suggestion. In Argentina, a woman's access may depend on her health-care providers' knowledge or attitudes, the general political atmosphere of the city or region, or the existence of a policy promoting access in cases of rape. For example, in Córdoba, a hospital director and a gynecologist averred that EC was available, but another hospital staff-member said that a directive had been issued ordering cessation of EC distribution. NGO representatives confirmed that women need to know a friendly doctor to obtain the drug or they self-medicate using regular contraceptives. Córdoba is the city where a court case was begun to prevent the sale of a dedicated EC product.<sup>5</sup> In Mar del Plata, rape survivors have access to EC because of collaboration between law enforcement authorities and the Commission on Women. The researchers noted, however, that access to EC was not a priority issue for many respondents.

Of the 14 women who filled out the questionnaire in Lesotho, 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 obtain it. In Nigeria, two focus-group participants had used EC and all said they knew where to get it, but none of the women who completed a questionnaire had tried to obtain EC. Twenty-seven of 40 NGO/health facility staff said they had no IEC materials on EC.

In Swaziland, one woman reported that she had needed EC but had not known how to obtain 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. A woman in South Africa spoke of her protracted and stressful experiences in accessing EC "after lengthy enquiries."

In Mexico, 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.

***Childbearing and infant feeding:*** The topics of childbearing, PPT, childbirth and infant feeding were not addressed specifically in the project benchmarks but some respondents

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<sup>5</sup> The case eventually reached the Supreme Court, which concurred in the ban of the product. EC is now sold in other formulations.

spontaneously talked about these aspects of reproductive health or answered country-specific questions on these issues.

NGO and HIV-positive respondents in Argentina, Botswana and Lesotho said that there is a lack of necessary information about safer pregnancy and childbirth. One woman in Lesotho 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." In Argentina, one physician commented that the lack of coordinated services was detrimental: "One would wish that we worked in a more coordinated way. It's a schizophrenic thing: we treat the pregnant woman until the day before childbirth. Then she goes to the maternity hospital for delivery, we lose her and she reappears four or five months later and we don't know what happened in connection with her HIV. These hospitals are only 50 blocks apart."

In both 2005 and 2006, respondents in Argentina noted that many health-care professionals, apart from physicians and gynecologists specialized in AIDS care, still believe that HIV-positive women should not be sexually active or think about having children. A staff member of an AIDS program in Bahía Blanca noted that until a few years ago, some HIV-positive women 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, although some respondents in Buenos Aires province said women should now be informed about the risks they run with pregnancy if they have high viral loads. A representative of a network of HIV-positive people outside Buenos Aires commented that women who now want a tubal ligation may do so after obtaining judicial authorization.

Women living with HIV in Botswana face a no-win situation of earning community, family and in-laws' disapprobation as *women* if they don't have children, and the disapproval of society, including government and health workers, as *HIV-positive women* if they do. This complicates their decisionmaking around pregnancy and family planning. In January 2006, a Member of Parliament stated in an interview for the government newspaper that he was concerned about "HIV positive women who continue to fall pregnant, saying they were contributing to the spread of the virus in the country" [79]. In response, the Botswana Network on Ethics, Law and HIV/AIDS (BONELA) and Bomme Isago Association issued a press release that was broadcast on radio nationwide pointing out that such statements "are counterproductive in fighting the epidemic .... In this era of HIV, everyone should be responsible. Men who are impregnating women are not equally being asked about engaging in unprotected sex" [80]. Such instances of blame have caused some HIV-positive women to feel stigmatized when they present to PPT programs already knowing their status. These women have felt unwelcome, told off and judged as irresponsible; consequently, some put off enrolling in PPT programs or choose to risk pregnancy without ART. Other women hesitate to reveal their HIV status to family-planning counselors because they do not want to hear that they shouldn't have sex or plan a family.

In Namibia, women commented on the fact that they have little decisionmaking power regarding whether to become pregnant. One woman told of pressure from her mother-in-law to have more children since the grandparents wanted more than two grandchildren. Even after she informed the woman that she and her husband were HIV-positive, the mother-in-law insisted that it was “un-African” to challenge in-laws’ wishes; she was forced to become pregnant and was awaiting the birth of triplets at the time of the focus-group discussions. On the other hand, young women in this country reported being told they will only receive ARVs if they consent to contraceptive injections since they should not have HIV-positive children that would place great burdens on the government.

Similar to the situation in Argentina and Botswana, HIV-positive women and NGO staff in Peru reported that some health professionals indicate HIV-positive women should no longer think about having sex and that pregnancy is contraindicated in their case. A representative of a feminist group said: “There is a strong prejudice if I am an HIV-positive woman. It seems that people think I no longer have a right to pleasure, I should not have sexual relations and even less so become pregnant....I remember that in workshops we did with health-care providers who are local decisionmakers, a prejudice emerged that affected women could not, should not — it was a mandate — get pregnant or have a sexual life.” A woman living with HIV confirmed this perception, relating how in numerous conversations her doctor persuaded her not to have children until she simply ignored his advice and became pregnant, ultimately giving birth to an HIV-negative child.

In Botswana, the respondents noted a number of other problems surrounding pregnancy. HIV-positive people have difficulties obtaining viral-load tests, although high viral loads may increase risks of HIV transmission during pregnancy; it is therefore difficult for women to make informed choices because they may know only their CD4 count and not their viral load.<sup>6</sup> The women felt that health providers decide whether to include certain drugs in ARV regimens on the basis of a client’s age or the number of children she already has, without finding out if the woman wants to have (more) children: “Sometimes the drugs that are given to women are based on their age... If they are going to give me a drug, I should know exactly what the side-effects of that drug are. If I’m going to be given a drug that will stop me from being able to have children, I should know about that and be offered [an] alternative. Or they ask you how many children you have ... ‘Oh, she already has 3, she won’t need any more.’ They don’t consult with you over this, or find out about your personal circumstance.”

In addition, women’s choices regarding PPT measures may be restricted. One woman related that she had asked for a cesarean section because she had genital warts and felt it would be safer for the baby not to pass through the vagina. The public hospital refused and she subsequently had the cesarean delivery at a private hospital, which she fortunately could afford.

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<sup>6</sup> A CD4 count of 200 or less is usually the point at which ART is started; it is assumed that low CD4 counts are associated with high viral loads and vice versa. However, it is possible for someone with a high CD4 count to actually have a high viral load.

Other women commented that health-care providers were not well prepared to offer ART when women give birth prematurely; one woman said: “The kid was not given anything and was never tested for HIV, because they didn’t know when to give the child the AZT [zidovudine]... syrup.”

In Namibia, women and infants are only followed-up for six weeks postpartum, yet are advised to breastfeed exclusively for four months and then to change to exclusive formula feeding. However, formula milk is difficult to obtain and/or use for many women; it is not freely provided by government hospitals, access to clean water is limited, and formula feeding can lead to involuntary disclosure. Women in Botswana also have difficulties keeping their HIV status private if they use replacement feeding provided by the government since the brand used is only available for PPT programs and not in stores.

***Abortion:*** The topic of abortion — or even postabortion care — appeared to be avoided by respondents in Kenya, Lesotho and Argentina (where it was only at the end of 2004 that provincial Ministers of Health agreed to formally provide postabortion care and legal abortions to all women, regardless of their HIV status). Four health-care professionals in Mexico spoke about abortion being taboo and illegal; several respondents in Poland mentioned illegal abortions among HIV-positive women they knew personally or through hearsay.

In Peru, a Ministry of Health official stated that a therapeutic abortion could be allowed if a fetus showed malformations or neurological problems but that a woman’s positive HIV status would not be an indication for therapeutic abortion. One woman living with HIV said that she consulted a psychologist about the risks of pregnancy when she was 1.5 months pregnant and feeling ill; the counselor advised her to have an abortion, but she had a miscarriage the next day. Another respondent said she knew of networks that assisted women to obtain safe, illegal abortions, but she was unsure whether they also helped HIV-positive women.

The three service providers who participated in the Namibian study said they offered no information or advice regarding emergency contraception, contraceptive failure or unwanted pregnancies, yet 85% of the focus-group participants said they had had an illegal abortion. A Namibian Member of Parliament, Rosa Namises, urged the government to reintroduce the Sterilisation and Termination of Pregnancy Bill of 1996 in the National Assembly, citing connections between women’s health, unwanted pregnancies, unsafe abortions and the AIDS epidemic. The government dropped the bill in 1999 after churches spearheaded protests against it. Ninety percent of Namibian focus-group participants felt that women or couples should decide on whether to have children or terminate pregnancies and that abortion should be legalized or more easily accessible. For example, although the concept of marital rape exists in law, police do not believe it is possible and women therefore cannot present proof of a crime and obtain a legal abortion in such cases.

While one HIV-positive focus-group participant in Nigeria said that abortion was not permitted by Islam, others stated that their reproductive rights should include the right to abstain from

sex, use family planning and terminate a pregnancy. One woman said: “Based on her medical record or level of infection, she has the right to tell her husband that they should abort the pregnancy or reduce the number of children they should [will] have.” Another woman commented: “We have a choice to make because if your husband cannot provide the needed care required, there is a need to stop childbirth, since the burden will be left for you as a woman to battle with at the end.” Eleven of 54 women who completed a questionnaire said they knew of an HIV-positive woman who had had an abortion but it was not indicated if this was legal or not.

The project coordinator in Kenya knew of one NGO that is providing treatment for the complications of unsafe abortion. The women in Botswana, Namibia and Swaziland said that some women travel to South Africa to obtain abortions. The Swazi focus-group discussants added that there is generally a lot of pressure to carry even unwanted pregnancies to term and to put babies up for adoption rather than have 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.

In Botswana, some women commented that workplace discrimination is common, with frequent demotions and termination of employment when an employee’s positive HIV status becomes known. Women are at increased risk of their status becoming known if they become pregnant; in addition, AIDS Service Organizations may dismiss pregnant women who work as counselors because they feel the women are no longer “good” role models. As a consequence, many women in such situations terminate pregnancies via clandestine abortions which carry substantial health risks.

The respondents in Botswana were of two minds regarding abortion, which emerged as a leading issue during their discussions. Some women felt it is for the couple, and not for the government, to decide whether a woman should or should not have a baby when a pregnancy is unwanted. They did not necessarily speak about it in terms of rights but in terms of necessity; one woman said: “We are not saying that we want abortion because we want that right. We are saying that we want abortion because there are circumstances in which people cannot cope with having a child. What about the women who are not able to negotiate the circumstances of sex? What about those whose partners leave them when they find out they are pregnant?” Other women argued that women who are in control of their sexuality are much less likely to end up with unwanted pregnancies, and that this control is what activist women’s groups should aim for rather than legalization of abortion: “I guess as an HIV-positive woman, our goal should be to be in control of our sexuality — we have sex when we want to, right? Now if we are saying that we end up with unwanted pregnancies, then we are consenting to this oppression of being made to have sex when we don’t want to have sex. Let’s try by all means to avoid pregnancy if

we don't want it. We have said...that we do have the right to get pregnant if we want to; we have also said that rights come with responsibility.”

Nevertheless, most of the respondents in Botswana felt that women should be able to choose whether to have a baby, albeit that the topic is taboo and rarely discussed openly: “People don't want to look at it as a fact. We know that people do it — we lose thousands and thousands of pula [Botswana currency] to women having abortions in South Africa — but we pretend it doesn't happen. So there's that woman there who has 15 kids at home because she is in an abusive relationship, and no-one to help her.” They also noted that the failure of the law to recognize marital rape complicates matters for women: “Marital rape doesn't exist as far as the police are concerned. If you go to the police and say that your husband has raped you, they'll laugh at you. They will tell you to go home and talk to your in-laws if you have a problem. In the law of Botswana my husband cannot rape me. The law says it's assault.”

In South Africa, the respondents said that 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 an abortion 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 dispose of it.

The South African support groups felt that most women do not know their rights and therefore agree to 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.”

**“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.”**

**Focus-group participants in South Africa**

TOP was also linked to forced sterilization, with women being told they would be given an abortion only on the condition that they agreed to be sterilized. The issue of forced sterilization was reportedly much worse in the rural areas.

## 2.4. PARENTING OPTIONS FOR HIV-POSITIVE WOMEN

### Premise

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 parenting options such as the availability of assisted conception methods and legal adoption by HIV-positive people [81].

### Findings

**Adoption:** None of the NGO representatives in Kenya said their organizations address legal adoption as a parenting option because "people are already taking care of orphaned children" or because it is "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. In Lesotho, three respondents said they had legally adopted children. Respondents in Nigeria commented that many HIV-positive women have informally adopted children of deceased family members or colleagues, without going through legal procedures. One focus-group participant had adopted three children, and 17 others were caring for children who had lost their parents to AIDS. In Namibia, 75% of the focus-group participants said they were caring for orphans and vulnerable children and 80% said they would adopt children as they felt it is their duty to look after orphans. In Poland, one NGO is actively mediating adoptions, although it seems that only HIV-positive children are placed with HIV-positive adults. <sup>7</sup>

None of the respondents in Mexico indicated that their institutions or programs had considered the issue of legal adoption by HIV-positive persons. 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. In Peru, on the other hand, respondents commented that legal adoption would be very difficult for HIV-positive people because of the strict requirements that are even posed for HIV-negative people. One HIV-positive woman was

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<sup>7</sup> The Federation noted that HIV-positive Polish children are also being adopted by HIV-negative couples in Germany and Italy.

in the process of qualifying as an adoptive parent but stated that it was a very complicated and arduous procedure. The Peruvian law on adoption demands that prospective adoptive parents submit a health certificate regarding infectious diseases such as HIV but it does not stipulate whether HIV infection would automatically disqualify a candidate.

Although the civil code in the Mexican 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. Two of the three women living with HIV expressed interest in knowing whether legal adoption could be an option for them.

Whereas adoption was scarcely addressed in the 2005 Argentinean study, the respondents in 2006 stated they supported adoption by HIV-positive persons. NGO representatives said they knew of people who wanted to adopt and considered this “a debt owed by society,” and representatives of HIV-positive people’s networks said members were now actively discussing this, although laws might have to be reviewed and this could take some time.

***Assisted conception:*** 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. In Namibia, focus-group participants had heard about artificial insemination because the coordinator of Lironga Eparu, an NGO serving HIV-positive people, announced on television that she had had the procedure. However, the respondents said they would be reluctant to ask health-care providers about the option because it might provoke further stigma and discrimination. The study in Poland mentioned one publicized case in which a couple was able to make use of assisted reproductive technology.

In Argentina, respondents mentioned that techniques such as sperm washing and in-vitro fertilization were available in the private sector but extremely expensive; in Peru, respondents said that even private insurance does not cover artificial insemination so that it would not be feasible for most HIV-positive women. One respondent outside Buenos Aires province commented on providing advice about “home remedies”: “We have managed the option of home insemination for couples with HIV-negative men and HIV-positive women; we have a bit of experience with this. When the positive person is the man, we talk about the idea of **diminished risk**: having sexual relations during the middle of the cycle without a condom... If the HIV-positive man is being treated, he may have an undetectable viral load: This is a way **to make people aware.**”

## 2.5. AVAILABILITY OF VCT AND PEP

### Premise

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 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 [22]. Ideally, women should be enabled to learn whether they are HIV-positive 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 can consider their options for protecting themselves against transmission. At the very least, women should have access to voluntary testing — accompanied by pre- and post-test counseling! — at facilities that they visit for other purposes such as family-planning services, STI centers, maternal and child health centers, nutrition programs and services offering postabortion care and legal abortion services or referrals.

In Lesotho, all citizens of reproductive age and older are being encouraged to have an HIV test; however, this program does not appear to provide counseling or information on the need for retesting in connection with window periods or exposure to risk situations. Botswana has instituted routine opt-out testing of all clients presenting to health services, but concerns have been raised about violations of the rights to informed consent and confidentiality [82]. The Namibian approach of training community-based counselors to promote testing may ultimately prove to be a more rights-based and effective approach.

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 and suffers genital trauma during the attack. This has been recognized by some governments through policies that aim to ensure that rape survivors are offered PEP if they report the crime soon enough to benefit from this form of antiretroviral treatment.

### Findings

**VCT:** According to many respondents, VCT centers are available in most large urban areas; in Poland, VCT is only available at specialized hospitals in large cities. However, access to VCT in rural areas often still leaves a great deal to be desired. For example, in Swaziland reaching VCT sites entails a significant journey for people living in isolated regions. Most respondents in Kenya, Lesotho, Nigeria and Swaziland appeared to know of VCT centers outside the public health system; however, the Nigerian focus-group participants commented that they mostly

received no pre- or post-test counseling. In Namibia, the focus-group participants had all received pre- and post-test counseling; their only complaint was that it had been difficult to have male counselors ask them intimate questions. In the Buenos Aires region of Argentina, some centers staffed by HIV-positive counselors have good reputations because they are known to particularly respect confidentiality.

In 2006, respondents in Argentina said that physicians have “internalized” antenatal testing, so that they do it routinely “and the women don’t object.” One HIV-positive woman commented, however: “The obstetric services follow the women who turn up positive when they are tested, but after they have the baby, there is no follow-up”. This occurs because the obstetricians would rather refer the women back to HIV services. In Mar del Plata, one respondent commented that: “Last year we had many cases of rapid tests during delivery; often the medicine (ART) was not available because you must order it in advance; in the private [maternity] centers they test the pregnant women without their consent.” At the VCT centers in Córdoba, Mar del Plata and Rosario, HIV-positive people are highly appreciated as VCT counselors.

In Peru, a Ministry of Health regulation supports couples counseling (especially focused on treatment adherence for persons found to be HIV-positive) and mandates inclusion of HIV-positive persons as counselors.

In Mexico, it was noteworthy 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 being done monthly. Another staff member of that hospital also affirmed that tests are done but said no counseling or accompanying support is provided. A staff member of an urban health center said that no women were diagnosed 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 was that no statistics concerning testing and referrals for testing are registered.

In Botswana, a problem for some women is that VCT counseling is not offered in the local language, Setswana; a considerable number of health-care workers have come from other parts of Africa, India and Cuba. The respondents further remarked that the practice of routine opt-out testing may be violating some rights. Given the shortages of health workers, it is more likely that people who already exhibit signs of HIV infection will be offered the test than people who appear perfectly healthy; a sickly appearance may also prompt health workers to offer a test. This brings up issues around confidentiality, stigma and discrimination. On the other hand, this practice means that people who are HIV-positive without symptoms might miss the opportunity to be tested. The women also commented that health-system clients may be subtly pressured into having a test without adequate preparation, information or support services to help cope with a positive test result. They said it is difficult for people to say no to a test because they see health providers as authority figures; some people might therefore put off seeking needed health care.

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.

It generally appears that many, if not most, women in the project countries still only learn of their HIV-positive status after antenatal testing. In addition, the Swazi focus-group respondents said that accessing the services may result in suspicion or unwanted disclosure for women who must obtain spousal or parental permission before traveling to a VCT center or visiting a health-service provider for any reason.

**PEP:** Provision of PEP for survivors of sexual assault appears to be a relatively rare occurrence according to the respondents in all project countries. While some respondents thought PEP might be available for rape victims, almost none said they knew women who had actually received it. In Peru, the Ministry of Health was just in the process of developing regulations for addressing gender-based violence and it was not clear whether PEP would be included.

In Argentina, government norms state that health-facility emergency rooms should have PEP kits with a month's supply of prophylactic drugs. In practice, availability of PEP is restricted to a few facilities that provide it in cases of work accidents or rape. There is no registration of the number of cases in which PEP has been provided, although in Córdoba respondents were aware of PEP because demand for it had risen as a result of a serial rapist who was attacking young women in that city. NGO and health-care providers did seem interested in promoting availability of PEP.

The project coordinator in Kenya 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.<sup>8</sup>

In Poland, 12 reference hospitals offered PEP in 354 cases in 2004, including 223 work-related exposures and 131 outside-work cases including rape, piercing with suspicious needles and attacks that involved piercing by drug users [60]. 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

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<sup>8</sup> In May 2006, the Inter Press News Service reported that only 7 of 73 district and one of 8 provincial hospitals in Kenya have PEP available [83]. Most private hospitals charge high fees for PEP; only the Nairobi Women's Hospital offers it free of charge.

work setting. It appears that the people exposed in such circumstances must pay for PEP and go to a reference site to obtain it.

The focus-group discussion in Lesotho revealed a significant lack of women-centered or maternal health services and even fewer rape-crisis services. Only three of the 14 survey respondents said that PEP is available for rape survivors.<sup>9</sup> Similarly, in Swaziland, there are reportedly no special health-care units for rape survivors. 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 Swazi respondents believed that PEP is available for survivors of rape or incest, and three mentioned hospitals where PEP is available. The other respondents 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.

In Botswana, four of 13 respondents said they would know where PEP could be obtained if needed. However, availability is restricted due to a limited number of sites offering PEP and a requirement that women report rape as a crime. Marital rape is not recognized and young women are reluctant to lodge formal accusations against male family perpetrators who bring income to the household. The project coordinator reported a case in which a young woman was raped and went to the police, asking them to take her for PEP. One police car was away on duty and another was being repaired, so that the law enforcement officers could not transport her; the project coordinator finally arranged for assistance [50].

In Mexico, respondents gave 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. One hospital director said that only pregnant women who have been raped are given ART, but 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 rape survivors had received PEP, indicating that it is apparently reserved for

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<sup>9</sup> In the second quarter of 2006, a gynecologist at a government hospital confirmed that PEP was not offered to rape survivors in Lesotho. However, the government and UNICEF organized a training seminar on services for rape and incest survivors for some 40 private and public health-care providers and members of the Christian Health Association of Lesotho which runs eight hospitals and 70 health centers [84].

occupational exposures. Apparently no statistics are registered on how many people actually receive PEP in Chetumal.

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; woman after woman told stories in the individual interviews and support groups about abusive intimate relationships in which 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.

## 2.6. HIV/AIDS-RELATED STIGMA AND DISCRIMINATION

### Premise

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 [85–87]. Some approaches to combating stigma are showing success [88], so we were interested in determining whether stigma and discrimination are still recognized as problems.

### Findings

***Within the health-care sector:*** 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. For example, in Argentina one comment was: “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.”

Nevertheless, some respondents and project researchers in Argentina and elsewhere knew of health facilities that provide high-quality care or had experienced improvements in care in recent years. Still, HIV-positive, health-care provider and NGO respondents in all 11 countries reported that stigma and discrimination against HIV-positive women persist within the health-care sector. The types of discrimination mentioned were remarkably similar across countries and regions; examples were:

- Judgmental, rude and humiliating attitudes
- Being made to wait while other patients are treated first

- Being denied counseling or attention during visits
- Demanding that the women provide gloves for examinations
- Breaches of confidentiality by doctors and nurses (in South Africa, a nurse even revealed a woman's status to the research team when they were visiting the facility)
- Being refused treatment or entry into hospital for childbirth (in Argentina, some hospitals only have one lab technician who will draw blood from HIV-positive persons or one gynecologist/obstetrician who will attend their births; in Peru, women have been denied pap smears and surgery for prolapse)
- Being denied medications
- Refusals to provide food or clean rooms during hospital stays
- Being treated improperly (in Lesotho, one woman was wrongly treated and then discharged with severe complications that caused a coma; in Botswana, a woman reported that a nurse squeezed pus from a boil using sticks and another said she received medication for thrush to treat herpes)
- Requiring participation in particular clinic-based support groups as a precondition for granting ART
- Forced sterilization (reported as a condition for abortion in South Africa and as a follow-up after a cesarean section for a woman who in Peru said she did not want a tubal ligation).

In Botswana, Namibia and South Africa, women reported mistreatment in connection with STI treatment and Pap smears; they said that nurses shout at them, call them illiterate and ignorant, laugh at and insult them. Women who return for Pap smear results are told that these are missing (South Africa), that it will take up to six to eight months to obtain results (Botswana), or they are not told they must return to obtain the results and hear whether follow-up is needed (Namibia).

Respondents in several countries also commented on the fact that ARV distribution is limited to certain well-known specialist centers so that anyone visiting these facilities to obtain their drugs will automatically be known as HIV-positive. In Namibia, one clinic even labeled two rooms as "Adult ARVs" and "Children's ARVs," thereby defeating the entire principle of confidentiality.

Denial of treatment, humiliation and stigmatizing attitudes were especially noted among health professionals who are not specialized in HIV/AIDS care. Polish respondents noted that HIV-positive women seek out gynecologists and health-care providers in larger cities who are known not to be "repulsed" by HIV-positive patients.

One focus-group participant in Namibia went to a hospital, where her presenting ailment was misdiagnosed. She had facial herpes but was only prescribed paracetamol, which did not improve her condition. She decided to go to a traditional healer, who made little cuts in her face, into which he rubbed black powder "from tree bark;" this exacerbated the condition. When she returned to the hospital, she was told she had herpes but no medications were available for treatment; she was told to come back after three days and then told to return a week later, but the medication was still not available at either of these visits. After six weeks, she finally received the medicine but it came too late and she lost one of her eyes.

Another woman in Namibia was told to take her child from the hospital ward where the child was admitted to a room which looked like a storeroom. She was told to put the baby on the table and leave it there; the health-care workers said the child did not have any chance of surviving so she was taking a bed that was needed for new patients who had chances of survival. The woman stayed with the baby for a day and half without any attendance from the nurses; the child finally died.

A third young woman in the same country was in the hospital with her child. When she told the nurses that her child was not responding to the medications they were giving, the nurses shouted at her. When the child became more seriously ill during the night in the ward, she was afraid to call the nurses again. Her child died in her arms.

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 contributes 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 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 respect include obtaining truly voluntary and informed consent, safeguarding confidentiality and ensuring proper counseling for women to be tested. It should be noted that the Ministry of Health in Peru has acknowledged the problem and worked together with an international NGO to develop participatory workshops on stigma for all health-care providers in the country.

***Outside the health-care sector:*** the South Africa project revealed that the HIV epidemic has given rise to new forms of abuse. Women in support groups and health-care workers reported that some women's 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 the women. Abuse by spouses or family members when a

woman discloses her HIV status, as well as domestic and sexual violence, were reported to be common occurrences in several countries.

Another form of HIV-related violence occurs in South Africa when husbands and partners send women to the clinics for ART and then take the drugs for themselves. The men do this to avoid counseling and some level of disclosure of their positive HIV status. Some women in one support group spoke of their husbands "finding drugs and throwing them away."

In Nigeria, a focus-group participant said that the opposite is occurring; men take ART but deny their wives the opportunity to seek treatment: "It is common knowledge that once your husband or partner discovers they are infected, they don't tell the wives and they will be taking ARV drugs secretly while starving the wife of sexual relationship. They will also refuse to take her to the hospital to know what disease has infected the woman until her case becomes hopeless and by then it has become too late to save her even with the ARV drugs."

## 3. Discussion and conclusion

### 3.1. CHALLENGES AND LESSONS LEARNED

Similarly to other studies, the project partners faced some challenges in collecting the data. In Argentina, Kenya and Nigeria, interviews and pick-ups of questionnaires sometimes had to be rescheduled several times. In Mexico, Peru and South Africa, some people approached for interviews declined to participate, although the numbers of refusals were small (one to three in each country).

During the first phase of the project, respondents in Kenya, Lesotho and Swaziland found that the sample questionnaire had too many questions. Other project partners suggested either splitting up some questions to make them clearer or adding questions to explore some issues further. It was also suggested that the order in which questions were posed be changed. The sample questionnaire was revised taking these suggestions into account; project partners further adapted the survey instruments.

Because some of the women involved in the ICW studies were illiterate or had little or no knowledge of English, ICW suggested including translation/interpretation possibilities in a future project. Ultimately, ICW questioned whether use of questionnaires was the best way to gather benchmark information from their particular respondents; they found that closely facilitated focus groups based on the benchmarks produced more useful information. They also suggested that the benchmarks be included in workshops that could guide women through a process of understanding their own experiences in the context of a political framework of rights, and of applying a gender analysis to their experiences. In their view, such an approach would make it easier to conclude discussions with suggestions for action and recommendations.

Organizing a one- or half-day workshop on data-collection methods, as GAF did, can enable organizations to build staff skills and more meaningfully involve affected women. As they stated: "We were ... 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 ... 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."

## 3.2. CONCLUSION

The monitoring tool project showed that provision of benchmarks, together with some very simple guidance on implementing a data-collection exercise, was sufficient to enable partners in different countries to collect information on the same topics. Because the respondents were not always familiar with the topics raised, the project gave the partner organizations an opportunity to simultaneously gather data and educate respondents about some issues. For example, in several countries interviewees were introduced to the Barcelona Bill of Rights and HIV-positive women learned about rights, as well as concrete information regarding health information and care (e.g., the desirability of regular Pap smears for women living with HIV/AIDS). As one respondent said: “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 (for example, violence against women) — that we don’t know about our rights. And Pap smears — I didn’t know about the importance of them.”

The project presented the staff and collaborators of some partner organizations with their first opportunity to engage in a simple research/data-collection exercise, thereby contributing to capacity-building among NGO staff and some women living with HIV. This was the case, for example, for team members in Botswana, Nigeria and South Africa, and it helped set the stage for possibly more formal research studies in the future.

Both project team members and respondents expressed appreciation for the opportunity to participate in the project, commenting that it was a learning experience and exercise in awareness-raising around important issues. Project coordinators also commented on the usefulness of the findings for their advocacy efforts; for example:

- “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.”
- In 2006, the Mexican coordinator said: “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. ... 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.” In 2006, she reported: “We have now obtained funding from a government agency to carry out a one-year project directed to HIV-positive women in Chetumal, based on the research we did.”
- “The project actually gave me the opportunity to do certain things I thought I could not. This is by sheer determination. ... The project also enabled me to reach out to many people in one way or another. ... We will use the report in our presentations during advocacy visits to policymakers and conferences for others to know what we have done and look for a way of solving the problems where necessary.” (PPFN)

The data collected by the different projects showed that much remains to be done if the MDGs are to be realized.

Knowledge about sexual and reproductive rights was lacking among many HIV-positive women in the various countries; health-care providers and policymakers also appeared to have limited information in this regard. If HIV/AIDS programs are to take a human rights-based approach, this knowledge gap must be bridged as a first step. Doing so can contribute to decreasing the stigma and discrimination faced by HIV-positive women when they present for care in the public and private health-care sectors. Interventions focused on human rights, stigma and discrimination can further promote greater meaningful involvement of affected and infected women in the formulation and evaluation of policies and programs.

Women need to know that engaging in VCT will produce benefits for themselves and their families. They will continue to avoid testing — or even avoid health services where testing is routine or opt-out only — if they fear humiliation, breaches of confidentiality, subsequent denial of care or abusive treatment when family members or providers learn their HIV status. If women believe that learning about a positive HIV status will enable them to better care for their health, gain access to ART when they need it and prolong their survival, they may be more willing to come forward for testing. VCT sites and services must be rapidly expanded, especially in more rural areas, and should involve HIV-positive women as co-managers, counselors and evaluators in order to improve their quality and relevance for other women.

If HIV/AIDS is to be addressed in a meaningful way, more attention must be paid to prevention measures that are especially relevant for women. For example, given the high levels of violence against women that still exist around the world, PEP must be made easily accessible and affordable, at least for survivors of sexual assault. In this regard, advocacy must ensure that victims of marital rape can also benefit from the service.

Finally, to help reduce maternal mortality, HIV-positive women must be able to make fully informed and voluntary decisions about pregnancy and parenting. They need relevant and specific information on all their fertility-regulation options, including contraception, EC and safe, legal abortion to end unwanted pregnancies. 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.

UN Secretary General Kofi Annan declared that to fulfill the 2001 UNGASS Declaration of Commitment on HIV/AIDS, states must “protect and promote the AIDS-related human rights of people living with HIV, women and children, and people in vulnerable groups, and ensure that they are centrally involved in all aspects of the response” [33]. The results of this monitoring tool project confirm that observation. The project partners hope that the tool and its benchmarks will form a useful resource in that regard.

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# APPENDIX 1: REVISED SAMPLE QUESTIONNAIRE

This questionnaire served as an example for phase 2 of the project.

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 any documents describing sexual and reproductive rights of HIV-positive women? If so, do you have copies on display or available for clients?
4. Would you be willing to display a copy of the Barcelona Bill of Rights in your facility?
5. Does your organization/program have available information and education materials on contraceptives that address which methods offer dual protection against pregnancy and HIV infection or reinfection?
6. Does your organization/program have available IEC materials that address use of emergency contraception?
7. Does your organization/program have available IEC materials on contraceptives that address possible interactions between hormonal contraceptives and drugs used to treat HIV and opportunistic infections?
8. If you don't have such materials available, why not?
9. Does your antiretroviral treatment program require women to use a particular contraceptive method? If so, which methods and why?
10. Are any measures available locally to help HIV-positive men and women conceive safely (e.g., sperm washing, in vitro fertilization, artificial insemination)?
11. What measures are available locally to help HIV-positive women give birth safely?
12. Does your program/facility offer emergency contraception without a prescription or as a prophylactic measure? If not, do you offer referrals on where women can get emergency contraception?
13. Does your organization/program have available IEC or counseling materials specifically for women living with HIV that discuss safe legal abortion for unwanted pregnancies?
14. If so, what kinds of materials are available?
15. Does your facility provide voluntary HIV counseling and testing services (VCT) or referrals to VCT?
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?
20. Do you know of women living with HIV who suffered discrimination within the health-care system? If so, what did this discrimination involve?

## APPENDIX 2: 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 3: STATEMENT OF COMMITMENT, ICW–BONELA WORKSHOP BOTSWANA

The respondents in Botswana formulated the following Statement of Commitment for Government, the Ministry of Health (MoH) and development partners to endorse.

1. The MoH should sensitize health–care workers on the reproductive rights of women living with HIV and AIDS, including the right to have children.
2. The Government should commit itself to ratify and domesticate treaties, protocols and conventions relating to gender equity because this has a direct impact on us as women and, especially, women living with HIV. [The treaties include all charters on human and people’s rights, on women’s rights in Africa and the Beijing Platform for Action.]
3. Development partners should commit themselves by supporting PMTCT programs and monitor their funds. Sometimes no milk is available in the clinic and women are forced to breastfeed. They need to be monitored for consistent access to all aspects of the program.
4. MoH should provide a comprehensive treatment and care package and provide adequate information and services on sexual and reproductive health (SRH). They should ensure that SRH issues are included in packages that already exist for HIV–positive women.
5. MoH must ensure that doctors and nurses prescribe medicines to HIV–positive pregnant women that are already on the shelf so as to improve availability and so that women don’t need to chase around looking for medicines. They should also prescribe medicines that aren’t available over the counter.
6. The shortage of gynecologists in the country should be addressed to help look after HIV–positive women who want to have children: one gynecologist in every ARV clinic.
7. Nurses should counsel women on family planning in relation to HIV and AIDS. At present, the HIV test is only offered when the nurse suspects that a woman might be HIV–positive. HIV counseling should become part of a family planning package.
8. Governments must consider the human–rights implications of policies that are being implemented.
9. Commit parliamentarians to push for implementation of action on this Statement.

## APPENDIX 4: CONTACT INFORMATION FOR PROJECT PARTNERS

Federation for Women and Family Planning  
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