



# HIV-positive women, MDGs & reproductive rights: Actions & research needed

In the year 2000, 189 United Nations member countries endorsed a Millennium Declaration in which they committed to making measurable progress toward the development of all nations by the year 2015.<sup>1</sup> Three Millennium Development Goals (MDGs) were identified that are especially important for the reproductive health of the more than 17 million women living with HIV/AIDS around the world today:<sup>2</sup>

- MDG 3: promote gender equality and empower women
- MDG 5: improve maternal health
- MDG 6: combat HIV/AIDS and other diseases.

To fulfill these three MDGs for the benefit of HIV-positive women, governmental and civil-society agents must now **take action** and **support research** that can inform policies and programs.<sup>3,4</sup>

*“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?”*

—young HIV-positive woman in Namibia

## Shorter-term actions needed to improve SRH services for HIV-positive women

### 1. Disseminate practical information on human-rights standards and ways in which women can claim their sexual and reproductive (SRH) 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. They need to

*“Capacity-building must be a two-way process so that governments, businesses and organizations also learn how to create meaningful involvement of women affected by and living with HIV/AIDS.”*

—recommendation from HIV-positive women in Swaziland

know which international rights treaties their government has ratified, to lobby for ratification of other relevant treaties and to monitor government compliance with these treaties. In addition, they should understand how rights can be claimed through laws and regulations, and know how private citizens can lodge complaints if rights are violated. This includes helping service providers and HIV-positive women identify where complaints can be addressed and providing them with support in following up on complaints, such as presenting cases to ethics committees of hospitals and professional medical associations, submitting cases to human-rights commissions and ombudspersons, and finding lawyers who can take well-documented cases to court if necessary.

### 2. 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 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. NGOs and universities can help enhance women's skills through training



and workshops on advocacy and policymaking, mentoring relationships, and internships on research and policy-oriented projects, in which women develop skills such as proposal writing, program design, strategic planning, documentation of program achievements, and monitoring and evaluation.

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### 3. Employ women living with HIV as paid educators and counselors

Many programs involve HIV-positive women in giving prevention messages — use condoms, get tested, be faithful — through talks and personal appearances. However, women living with HIV are rarely asked what kinds of messages would have drawn their attention before they learned their serostatus (for example, what messages might have motivated them to have an HIV test sooner than they did?). HIV-positive women should be paid to help formulate prevention policies and messages. Health systems should also pay HIV-positive people as educators and counselors.

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

Much HIV/AIDS-related advocacy has focused on preventing perinatal transmission and expanding access to antiretroviral drugs (ARVs). In comparison, relatively little attention has been given to ensuring sexual and reproductive health needs and rights, such as:

- Screening and treatment of sexually-transmitted infections (STIs) and reproductive tract infections (breast and cervical cancer)
- **Provision of adequate antenatal, delivery and postnatal care for HIV-positive women and infants**
- Improving information about, and options for, infant feeding by HIV-positive women

- Improving access to post-exposure prophylaxis (PEP) for HIV-negative women
- Ensuring that programs to address violence against women and girls include provision of psychological and legal aid, emergency contraception, STI screening and treatment, and access to safe legal abortion
- Incorporation of postabortion care into HIV/AIDS programming
- Increasing access to safe legal abortions for pregnancies that HIV-positive (and other) women do not want.

In all these cases, advocacy should involve three 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; and training of HIV-positive women so that they can demand appropriate services.

### 5. Prepare and publish information and counseling materials on family planning in the context of HIV/AIDS

All HIV-positive people, including both adults and adolescents, need to be informed about the double protection offered by male and female condoms against HIV re-infection and unwanted pregnancy. They also need family-planning information and counseling that addresses concerns such as the advantages and disadvantages of different contraceptives for HIV-positive women in different situations; potential

interactions between hormonal contraceptives, ARVs and drugs for opportunistic infections; failed contraception and emergency contraception; and safe abortion for indications permitted by law.

While many HIV-positive people, particularly younger women, want to



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become pregnant, others are interested in adopting children. NGOs should ascertain whether legal and regulatory restrictions 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 HIV-positive people to discuss how they can ensure that HIV-positive people are not automatically disqualified as prospective adoptive parents. Testimonies and stories about successful adoptions can be shared through newsletters, websites and conferences.

## 6. Ensure that the health system addresses both wanted and unwanted pregnancies in relation to HIV/AIDS

Progress has been made around the world in expanding measures to prevent perinatal transmission of HIV, but little has been done to address the needs of HIV-positive women facing unwanted pregnancies.

Counselors who have grown accustomed to speaking only about prevention of perinatal transmission must learn to inform women in a nonjudgmental and noncoercive way about their options in connection with unwanted pregnancies. Given gestational limits on abortion, when possible, counselors should encourage women to make decisions on whether to continue pregnancies as early as possible. Counselors further must ensure that women know they always have a right to postabortion care, even where indications for abortion are restricted by law. All new guidelines and manuals concerned with abortion care should give specific attention to potential clients with HIV, and all new guidelines and manuals related to reproductive health, pregnancy and HIV should incorporate the topics of emergency contraception, unsafe abortion and abortion-related care.

Networks and coalitions must collaborate to include post-abortion care for miscarriages and unsafe abortions in policies and programs. NGOs and other agencies should advocate for women's access to safe abortions for all indications permitted by law, as well as law reforms to expand access. Program managers and health-service providers must be adequately trained to provide referrals and services related to HIV and abortion care. Given the stigma and discrimination that affect both HIV infection and pregnancy termination, it would be



*"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."*

– focus group of HIV-positive people in Nigeria

useful to incorporate values clarification about both issues in training, so that providers do not refuse any legal SRH services to HIV-positive women.

Reproductive health counselors and physicians should be

familiar with all indications for abortion permitted by law, and providers of abortion care should be sensitized to the special needs of women living with HIV/AIDS. Most health facilities that provide abortion care are not equipped to offer voluntary HIV counseling and testing (VCT), but they should be able to refer clients to VCT services, support groups for people living with HIV/AIDS and health facilities offering antiretroviral therapy.<sup>5</sup>

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

*"It is therefore important to guard against policies that abuse the rights of HIV-positive women including those that incorporate involuntary procedures, such as forced caesarean births, forced abortion or sterilisation, or limited or no access to abortion."*

– N.M. Naylor<sup>6</sup>

From a gender perspective, it is important that HIV-positive women be involved in monitoring whether policies and programs are including measures such as those mentioned above. It is important to engage more women in gathering information and evidence on which advocacy and community action can be based. They must also be enabled and supported to publicly present their findings and recommendations at meetings, press conferences and technical consultations. This will increase the visibility and recognition of women's contributions to increasing the knowledge base concerning the epidemic and its effects.

# Research needed to improve reproductive health services for HIV-positive women

The following list of research topics shows areas that have been neglected and for which we need to build an evidence base for improved policy formulation and service provision.

## Social science and policy research

- Incorporation of HIV-positive women in reproductive health counseling as paid counselors and anti-stigma educators for health-care personnel
- Effectiveness and impact of advocacy and policy capacity-building in helping people living with HIV/AIDS enjoy complete SRH rights
- Factors that enhance and impede knowledge about, and access to, screening and treatment for reproductive-tract infections and cancers
- Ways to increase couples' communication about pregnancy planning and parenthood
- Problems that HIV-positive women in urban and rural areas, and of different occupational backgrounds, experience with infant feeding (breastfeeding and replacement feeding)



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- Factors that can promote safer breastfeeding for HIV-positive women (e.g., heat treatment of breast milk)
  - Obstacles to HIV-positive people being able to foster and/or adopt children (especially in Latin American, Eastern European and industrialized countries)
  - How women living with HIV cope with unwanted pregnancy
- Social, legal and health-service obstacles impeding adolescents, regardless of their known HIV status, and HIV-positive women from accessing safe nondiscriminatory abortion care and postabortion care
  - Social, legal, institutional and funding obstacles to linking HIV/AIDS services and abortion-related care
  - Methods, effectiveness and impact of linking HIV/AIDS services and abortion-related care
  - Adolescents' and HIV-positive women's experiences with abortion-related care.

## Clinical service provision

- Health-system obstacles and solutions to ensuring that HIV-positive women are offered screening and treatment for reproductive-tract infections and cancers (education on self-breast examinations, mammograms, Pap smears, etc.)
- Education of women and men living with HIV (especially discordant couples) on "home methods" of artificial insemination
- Unsafe abortion and HIV/AIDS: severity of complications, best practices for postabortion care
- Reproductive counseling in relation to HIV/AIDS: message content; specific needs of HIV-positive women; incorporation of reproductive rights and information about dealing with failed contraception and unwanted pregnancy
- Abortion methods and stage of HIV infection: comparative efficacy and sequelae in HIV-positive women who are asymptomatic, symptomatic but not on ARVs and women who are on ARVs
- Abortion methods and possible considerations regarding HIV infection (e.g., precautions related to a higher risk of anemia, infection prevention, interactions of medication abortion drugs and ARVs).

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P.O. Box 5027  
Chapel Hill, NC 27514, USA  
Tel: +1-919-967-7052  
<http://www.ipas.org>

Written by Maria de Bruyn  
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