

Sexual and Reproductive Health of Women and Adolescent Girls Living With HIV

guidance for health managers, health workers, and activists

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Coordination

EngenderHealth, UNFPA, and the David & Lucile Packard Foundation

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EngenderHealth and United Nations Population Fund (UNFPA)

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ORGANIZING INSTITUTIONS



EngenderHealth is a leading international reproductive health organization working to improve the quality of health care in the world's poorest communities. EngenderHealth empowers people to make informed choices about contraception, trains health professionals to make motherhood safer, promotes gender equity, enhances the quality of HIV and AIDS services, and advocates for positive policy change. The nonprofit organization works in partnership with governments, institutions, communities, and health care professionals in more than 25 countries around the world. For 65 years, EngenderHealth has reached more than 100 million people to help them realize a better life. For more information, visit www. engenderhealth.org.



Fundo de População das Nações Unidas

The **United Nations Populations Fund (UNFPA)** is an international cooperation agency for development that promotes the right of every woman, man, young person, and child to live a healthy life, with equal opportunity for all. It supports countries in their use of social and demographic data for formulating policies and programs directed at reducing poverty. It contributes to ensuring that all pregnancies are desired pregnancies, that all childbirth is safe, that all young people are free of HIV and AIDS, and that all women and girls are treated with dignity and respect. For more information, visit www.unfpa.org.br.



The David & Lucile Packard Foundation was created in 1964 and invests in and takes smart risks with innovative people and organizations to improve the lives of children, enable the creative pursuit of science, advance reproductive health, and conserve and restore earth's natural systems. The Population Program at the David & Lucile Packard Foundation invests in pioneering organizations and individuals that strive to give women and their families the ability to decide how many children to have and when to have them, and to receive proper medical attention when they do. They are working toward a future where the governmental, nongovernmental, and private sectors can join in helping all individuals to fully exercise their reproductive rights through access to services like antenatal and postnatal care, sex education, contraception, and emergency obstetric care. This will have a lasting impact on families and communities throughout the world. For more information, visit www.packard.org.

Partner Organizations



Movimento Nacional Cidadas PositHIVas (MNCP) National Movement of PositHIVe Women Citizens

The MNCP is a Brazilian organization of women living with HIV and AIDS; it was created to promote the empowerment of women with any degree of seropositivity for HIV, irrespective of creed, sexual orientation, race, color of skin, ethnic group, or political party, in the municipal, state, regional, and national spheres. The empowerment process consists of establishing action strategies that lead women to accept their positive HIV serological status, to monitor public policies, and to exercise their citizenship to the full (thereby combating isolation and inertia); promoting the sharing and exchange of experiences; and improving their quality of life. A further principle of the movement is engaging in HIV prevention work with noninfected women, as part of the efforts to control the epidemic in Brazil.



ICW Brasil—Brazilian Chapter of the International Community of Women Living with HIV and AIDS (ICW)

ICW is the only international network made up exclusively of women living with HIV and AIDS and entirely run by them. Its objectives are: to bring together women living with HIV and AIDS to discuss the problems that affect them; to ensure that the voices of these women are heeded; to serve as a source of medical, legal, and social information; to challenge and contest discrimination and stigmatization; to denounce violations of the rights of women living with HIV and AIDS; and to contribute to the empowerment of women living in that situation. (web site: www.icw.org/; e-mail: icwbrasil@icwlatina.org)



RNP+—National Network of People Living with HIV and AIDS

RNP+ Brasil is a national network of people living with HIV and AIDS; it has no religious or partisan political ties, and it is active in promoting the strengthening of people who are seropositive for HIV, irrespective of gender, age-group, sexual orientation, creed, race, color of skin, ethnic group, or nationality. (web site: www.rnpvha.org.br/)



UNGASS Forum—Brazil

The United Nations General Assembly Special Session on HIV and AIDS (UNGASS AIDS) was held in June 2001 and led to the Declaration of Commitment on HIV/AIDS, which consists of 113 goals for combating AIDS in the world up until 2011 and which was adopted by 189 member countries. Civil society has been active in monitoring governments' goals. In Brazil, the monitoring of the UNGASS AIDS goals is an initiative of GESTOS (Seropositivity, Communication, and Gender) and of GAPA SP (Support and Prevention in AIDS Group). The work has been undertaken ever

since 2003 and has inspired other countries in Latin America, the Caribbean, Africa, and Asia. (web sites: www.gestos.org and www.gapabrsp.org.br/)

Grupo de Incentivo a Vida (GIV)—Incentive for Life Group

The GIV is a mutual aid group for people who are HIV-positive; it too is run by people living with HIV. It is a nonprofit group entirely free of any prejudices, partisan political, or religious connections. Its mission is to propagate ways to ensure a better quality of life for those living with HIV and AIDS, not only in the social sphere but also in the areas of physical and mental health.



Grupo de Apoio e Prevenção à AIDS (GAPA)—Support and Prevention in AIDS Group

GAPA's institutional mission is to defend human rights and support the integration into society of people living with HIV and AIDS. Its objectives are to fight for the establishment of an effective public health policy in regard to AIDS in Brazil and to engage in legal battles against discrimination and behavior that infringes on the human rights of people living with HIV and AIDS. (web site: www.gapabrsp.org.br/)



GESTOS (Seropositivity, Communication, and Gender)

Founded in May 1993, the objective of GESTOS is to defend the human rights of HIV-positive people and of populations vulnerable to sexually transmitted infections and HIV. GESTOS produces and makes use of knowledge in and from many fields and is active in education, communications, and public policy, always from a perspective of sexual citizenship, gender equality, and social justice. (web site: www.gestos.org/)



The Joint United Nations Programme on HIV and AIDS (UNAIDS)

Concern about the advance of the HIV and AIDS epidemic in the world and the need for a global response resulted in the creation of UNAIDS in 1996. Cosponsored by 10 agencies of the United Nations system, its global mission is to lead, strengthen, and support a broad response to HIV and AIDS so as to halt the advance of HIV, offer treatment and assistance to those infected and affected by the disease, reduce the vulnerability of individuals and communities to HIV and AIDS, and alleviate the socioeconomic and human impacts of the epidemic (web site: www.onu-brasil.org.br/agencias unaids.ph).



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Foreword

People living with HIV and AIDS (PLHA) have the right to freely choose whether or not to have children; how many to have and when to have them; and to have access to integrated health services promoting care and attention to sexual and reproductive health (SRH), including family planning (FP), prevention of HIV and AIDS and other sexually transmitted diseases (STDs), for themselves and their partners. The right to sexual and reproductive health extends to all men and women, irrespective of their serological status for HIV.

Nevertheless, the rights of women and adolescent girls living with HIV are not always recognized or given priority in policies and programs, particularly their reproductive rights. The international community has widely and definitively declared that PLHA have the right to integrated health care that takes into account their own decisions in regard to SRH and to have the information necessary to make those decisions. However, many countries still lack policies and programs that protect the sexual and reproductive rights of PLHA or that take into consideration their specific SRH needs.

Until recently, the SRH of women and adolescent girls living with HIV and AIDS has been almost exclusively addressed in terms of the prevention of mother-to-child transmission of HIV, and furthermore has been focused primarily on the needs of the child. As treatment for HIV and AIDS becomes more accessible in many countries, women, men, and young people are able to plan their futures and make decisions concerning their sexuality and reproduction. Even so, PLHA still have a series of problems to face, including disclosure of their HIV status to family members and their partners, difficulties in negotiating safe sex strategies with their partners, access to contraceptive methods, and the means to prevent vertical transmission of HIV and syphilis and gender-based violence in both their personal relationships and in the community.

There are many challenges to promoting SRH and preventing HIV among women and girls, and these are strongly influenced by macro-structural factors such as poverty, gender inequality, racial discrimination, stigmatization, and issues more directly related to the organization of the services and the training and qualification of health workers in that field. Therefore, ensuring access to quality SRH services for women and adolescent girls means contributing to an

effective global response in confronting the dissemination of HIV and poverty, racial discrimination, gender inequality, and gender-based violence. Recently, the international community has broadened its support for efforts to strengthen the linkages between SRH and HIV in the policy and programming spheres, as a way of ensuring universal and equitable access to primary health care. Behind such global commitments is the recognition that in spite of their having access to antiretroviral (ARV) treatment, the SRH rights of growing numbers of men and women living with HIV are not being respected in practice. That situation is even more complex in regard to highly vulnerable populations such as men, women, and young people living in extreme poverty or destitution or in situations of sexual exploitation and trafficking; injecting drug users; sex workers; and men who have sex with men.

Nowadays, it can be seen that in addition to their being consonant with the rights and needs of health service users, SRH care and attention and HIV-related care need to be closely associated; this is also a means of making better use of resources that are often in short supply. That is one of the pathways that have been traced out for achieving the goals agreed to internationally at the United Nations General Assembly Special Session on HIV/AIDS (UNGASS), the International Conference on Population and Development, and the Millennium Development Goals. Among those goals are the reduction of maternal mortality, the attainment of universal access to HIV prevention and to FP, and treatment for and reduction in the numbers of cases of HIV and AIDS.

In that sense, there is an urgent need to intensify efforts to develop new strategies for integrated action and new instruments for monitoring and evaluating impacts; to increase resources; and to ensure transparency in administration and management and in the commitment of managers, activists, and professionals working in the fields of integrated health care and the prevention of and assistance with HIV and SRH. This document sets out some contributions toward guaranteeing that the right to health and the right to SRH of women and adolescent girls living with HIV and AIDS are totally and integrally protected, promoted, and guaranteed.

Paul Perchal and Alanna Armitage

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Abbreviations and Acronyms

AIDS acquired immunodeficiency syndrome

ARV antiretroviral (drug)

CEDAPS Health Promotion Center

CNS Health National Council

DAPES Department of Programmatic and Strategic Actions

ECOS Sexuality Studies and Communication

GAPA AIDS Support and Prevention Group

HIV human immunodeficiency virus

ICPD International Conference on Population and Development

ICW Brasil

Brazilian Chapter of the International Community of Women Living with HIV and AIDS

MNCP National Movement of PositHIVe Women Citizens

MOH Ministry of Health

PLHIV people living with HIV

SAS Health Care Department

SEPPIR Department of Policies and Programmatic Racial Equality

SPE Health and Prevention in the School Project

Special Department of Policies for Women

SRH sexual and reproductive health

SRRR sexual rights and reproductive rights

sexually transmitted disease

SUS Unified Health System

SVS Health Surveillance Department

UNAIDSJoint United Nations Programme on HIV/AIDS

UNFPA United Nations Population Fund

United Nations General Assembly Special Session

WHO World Health Organization

1 Introduction

Background

The number of cases of HIV and AIDS among women and adolescent girls in Brazil has been gradually increasing since the epidemic began. In the period from 1980 to June 2007, were identified 314,000 cases of AIDS among males and 160,000 among females¹. The Brazilian response has been considered to be the best in the world; it was guided by the principles of the Unified Health System-SUS—namely, universality, integrality, equality, decentralization, and social participation. Its success stems from the convergence of multiple elements, among which are: the development of a National Programme for the Prevention and Control of Sexually Transmitted Diseases (STD) and AIDS that defines, directs, and regulates the prevention, control, assistance, care, and support actions in the states and municipalities; the close partnerships established with other governmental and nongovernmental sectors; and, above all, the universal distribution of antiretroviral (ARV) therapy—a decision that has led to the marked

decline in AIDS-related mortality rates clearly described in the most recent UNAIDS report².

Right from the time when the first cases were identified, the AIDS epidemic has struck at young people. The first AIDS case in that age-group was identified in 1982. Since then, 54,965 AIDS cases have been identified in Brazil, of which 10,337 were among 13-19-year-olds and 44,628 were among 20-24-year-olds. HIV transmission among young women is predominantly heterosexual: In 2006, the ratio between the sexes hit the mark of 0.6:1, meaning that for every six cases among men, there were 10 among women. These ratios corresponded to incidence rates of 1.7 per 100,000 male inhabitants and 2.8 per 100,000 female inhabitants. If we take as our reference the overall Brazilian population (in which men outnumber women), then it can be seen that the feminization of the epidemic is occurring much faster among young people and adolescents, especially among those aged 13-193.

BRASIL. Ministério da Saúde. Secretaria de Vigilância em Saúde. Programa Nacional de DST/AIDS. Boletim Epidemiológico AIDS e DST July-Dec. 2006; 2007 Jan.-June. Ano IV, n. 1. Brasília: MS, 2008.

UNAIDS Report, August 2008 www.AIDS.gov.br/data/Pages/LUMIS29D2BB4DPTBRIE.htm. Accessed on September 18, 2008.

BRASIL. Ministério da Saúde. Secretaria de Vigilância em Saúde. Programa Nacional de DST/AIDS. Boletim Epidemiológico AIDS e DST jul-dez 2006; 2007 Jan.—Jun. Ano IV, n. 1. Brasília: MS, 2008.

Although the policies that have been followed up to the present have achieved a deceleration of the epidemic in absolute terms, they have also produced gradual changes in the patterns of its progression and have led to what has been called the "pauperization" of the epidemic⁴. Gradually but detectably, HIV cases have become more common in the smaller towns; the epidemic has also become more juvenile and more heterosexual. According to the Integral Plan for Confronting the Feminization of AIDS and other STDs, which was launched in March 2007, the number of AIDS cases registered among women increased by 82% from 1995 (7,280 cases) to 2005 (13,249 cases). Another important piece of information is that even though universal access to treatment has had a positive impact on the quality of life and has reduced AIDS mortality rates throughout the country, the number of AIDS-related deaths among women has increased notably⁵.

This information confirms the fact that efforts to address the feminization of the epidemic cannot be restricted to providing access to ARV drugs alone. There must be investments in promoting the health of people living with HIV and especially the sexual and reproductive health of women. adolescent girls, and young people in general. Furthermore, those actions need to be accompanied by policies designed to reduce socioeconomic, racial, and gender inequality and to foster social inclusion and the empowerment of women, so that women may be properly recognized and protected and have their rights to autonomy and freedom in regard to their own bodies at all stages of their lives fully guaranteed as a fundamental dimension of health and life. Men's participation in SRHrelated issues and their engagement in defending and promoting the rights of women, including sexual and reproductive rights, also need to be promoted.

Listening to Brazilian women living with HIV, it becomes very clear that despite all of the political commitment, the efforts made, and the achievements (access to the promotion of integrated health;

^{4.} Kalichman, A., 1994. Pauperização e banalização de uma epidemia. In: Seminário "A Epidemiologia Social da AIDS", Anais, pp. 20–26, Rio de Janeiro: Associação Brasileira Interdisciplinar de AIDS/Instituto de Medicina Social, Universidade do Estado do Rio de Janeiro.

BRASIL. Ministério da Saúde. Plano integrado de enfrentamento da feminização da Epidemia de AIDS e outras DST. Ministério da Saúde: Brasília, 2007. Available: http://www.AIDS.gov.br/data/Pages/LUMIS9DAF1EC6PT-BRIE.htm. Accessed on July 18 2008.

prevention of disease; care and treatment), challenges still have to be met in regard to addressing the needs of women and adolescent girls, especially their sexual rights and reproductive rights.

A diagnosis of HIV infection has considerable repercussions in the daily lives of women: the difficulties they face in revealing the situation to their families and/or their sexual partners; their lack of real knowledge about the question of reinfection and about infection with other STDs; the need to insist on consistent condom use; and the impact on their desire to have children or not to have them.

A report stemming from the UNGASS-Brazil Forum in 2008⁶ identified a number of difficulties and created indicators with a view to improving "positive prevention"⁷ and the SRH care being offered to people living

with HIV (PLHIV). Among the points discussed, special emphasis was placed on giving people access to new technologies in assisted reproduction, broadening their access to health services, and promoting and fostering equality of sexual rights and reproductive rights for PLHIV of both sexes, in all age-groups, from a gender perspective, and with guaranteed investments in the qualifications of all the professionals who need to be involved.

Indeed, the need to prepare health staff to recognize, promote, and put into effect the sexual rights and reproductive rights of women and adolescent girls living with HIV and AIDS and to meet their needs in this area has appeared in several of the surveys carried out in Brazil^{9, 10}.

The risks of mother-to-child transmission of HIV during pregnancy,

Every day, I quarrel with my husband because he will not agree to use a condom. He is not sure whether he has the virus or not because he doesn't want to take the test. I keep telling him we need to protect ourselves, but whenever I insist, then we have a war on our hands. So I usually end up going along with him, even though I know the risk we are running of reinfection.

28-year-old woman living with HIV¹¹

^{6.} UNGASS AIDS Forum Brazil: Monitoring UNGASS-AIDS goals in Sexual Health and Reproductive Health of Women.

^{7.} Positive prevention is aimed at people living with HIV. www.AIDS.gov.br, site consulted on September 18 2008.

^{8.} Brasília, Ministério da Saúde, Marco Teórico e Referencial: Saúde Sexual e Reprodutiva de Adolescentes e Jovens, Brasília, Ministério da Saúde, Secretaria de Atenção à Saúde, DAPES, 2006.

Paiva, Vera. Lima, Tiago. Santos, Naila et alii, Sem Direito de Amar?: A Vontade de ter Filhos entre Homens (e Mulheres) vivendo com o HIV, Psicologia USP, 2002, v. 13, n. 2, p. 105–133, Disponível em: <www.scielo.br/ scielo.php?script=sci_arttext&pid=S0103-65642002000200007&Ing=pt&nrm=iso> Acessado em 29/07/2008.

^{10.} Kurokawa e Silva, Neide Emy; Alvarenga, Augusta Thereza; Ayres, José Ricardo de C M, Aids e gravidez: os sentidos do risco e o desafio do cuidado, em Aids e gravidez: os sentidos do risco e o desafio do cuidado, em http://www.scielo.br/pdf/rsp/v40n3/16.pdf site consultado em August 18, 2008.

^{11.} Statement collected during the survey Sexual and Reproductive Health Needs of Women and Adolescent Girls living with HIV, Research Report for Qualitative Findings from Brazil, Ethiopia and the Ukraine, Brazil/Ethiopia/ Ukraine, EngenderHealth and UNFPA, 2006, Available at: www.unfpa.org/upload/lib_pub_file/619_filename_ SHRH-of-hiv-positive-women.pdf.

birth, and breastfeeding are clear¹². In regard to both HIV and syphilis, considerable progress has been made in Brazil, particularly after the Brazilian prevention protocol¹³ was established, but there are still challenges that need to be met.

One of those challenges concerns the qualifications of health workers. Many of them still find it difficult to approach questions related to the sexuality and the reproductive health of women and adolescent girls living with HIV. According to Paiva and her collaborators¹⁴, we need to ask ourselves why the desire of health workers to reduce vertical transmission translates into denying patients their right to information and counseling, or why it is so difficult for health workers to acknowledge the desires of men and women living with HIV and AIDS to make their reproductive decisions in a free and well-informed manner or to encourage them to do so.

Kurokawa and her collaborators 15 have stated that the difficulties that health workers have in that regard, and which are reflected in the services they provide, prevent them from truly accepting the specific needs of that group of women and consequently from guaranteeing that their right to integrated health care is put into practice effectively. In the context of antenatal and maternity care services, services focused on that group should be structured as a set of interventions made by the team and adapted to the real possibilities of each service and the specific needs of the women. Health workers need to undergo capacity building to ensure that they adopt correct conduct and procedures throughout the antenatal period, during delivery, and in the postpartum period.

Even when the restrictions related to transmitting HIV to infants are taken into account, many women living

^{12.} Vertical transmission of HIV occurs through the passing of the virus from the mother to the baby during pregnancy or labor or at the moment of birth itself (through contact with the cervical-vaginal secretions and maternal blood) or through breastfeeding. < www.aids.gov.br>. Accessed August 8, 2008.

^{13.} BRASIL, Protocolo para a prevenção de transmissão vertical de HIV e sífilis Ministério da Saúde - Secretaria de Vigilância em Saúde - Programa Nacional de DST/ Aids, em http://www.saude.rio.rj.gov.br/media/dstaids_gestante_protocolo_out06.pdf Accessed on August 18, 2008.

^{14.} Paiva, Vera. Lima, Tiago. Santos, Naila et alii, Sem Direito de Amar?: A Vontade de ter Filhos entre Homens (e Mulheres) vivendo com o HIV, Psicologia USP, 2002, v. 13, n. 2, p. 105-133, Disponível em: <www.scielo.br/scielo.php?script=sci_arttext&pid=S0103-65642002000200007&Ing=pt&nrm=iso> Accessed July 29, 2008.

^{15.} Kurokawa e Silva, Neide Emy; Alvarenga, Augusta Thereza; Ayres, José Ricardo de C M, Aids e gravidez: os sentidos do risco e o desafio do cuidado, em Aids e gravidez: os sentidos do risco e o desafio do cuidado, em http://www.scielo.br/pdf/rsp/v40n3/16.pdf site consultado em August 18, 2008.

with HIV offer consistent arguments to justify their wish to have children. Outstanding among them are the opportunity to live or relive the experience of being a mother or of constituting a family. Kurokawa and her collaborators show that society forcefully represents reproduction as being a basic feature of female identity¹⁶; other motivations are also in play, such as the male conjugal partner's expectations of what the woman will offer in exchange for the affection he has bestowed on her or for his gesture in taking her as a partner.

Although many PLHIV may express a desire to experience maternity/ paternity, some among them formally decide not to have children. There are many gaps in knowledge concerning contraceptive methods for women and adolescent girls living with HIV and AIDS, such as the effects of hormonal contraception (in terms of menstrual disturbances, their impact on the evolution of the disease, and their interactions with ARV medicines).

To reduce the risks of unintended pregnancy, acquisition of other STDs, or HIV transmission to partners, dual method use (i.e., consistent use of condoms along with another safe contraceptive method) is recommended; this recommendation should be an integral part of counseling on sexuality and reproduction carried out by professional staff qualified to deal with adult women and/or adult couples and adolescents and with young people living with HIV and AIDS, whether they are seroconcordant or not¹⁷. In a 1998 study of women's adherence to the use of combined methods of contraception, it became clear that adherence to double protection was heightened among women who had received counseling on sexuality and reproductive health¹⁸.

Counseling should not be sporadic or linked to specific occasions (posttest, postpregnancy) and instead should become part of a continuous process, being adapted to all stages of the infection and

^{16.} Kurokawa e Silva, Neide Emy; Alvarenga, Augusta Thereza; Ayres, José Ricardo de C M, Aids e gravidez: os sentidos do risco e o desafio do cuidado, em Aids e gravidez: os sentidos do risco e o desafio do cuidado, em http://www.scielo.br/pdf/rsp/v40n3/16.pdf site consultado em August 18, 2008.

^{17.} Santos, Naila e cols Mulheres HIV positivas, reprodução e sexualidade http://www.scielo.br/pdf/rsp/v36n4s0/11159.pdf Accessed on September 18, 2008.

^{18.} Magalhães, J., Mulheres Infectadas pelo HIV: O Impacto na Anticoncepção, no Comportamento Sexual e na História Obstétrica. Dissertação de Mestrado, Campinas: Departamento de Tocoginecologia, Faculdade de Ciências Médicas, Universidade Estadual de Campinas, 1998.

to all stages of the client's life. Continuity between primary and secondary prevention must be intensified; proposals for prevention programs, always directed at seronegative groups, must now go beyond the habitual "training" in condom use that ignores cultural obstacles and the social contexts in which the women live and which are just the same after the diagnosis as they were before it. Investment in counseling should include the formation of specialized, interdisciplinary teams that can serve as a reference for direct attention to the client or serve to support the regular work and practices of the doctors, nurses, and attendants, social assistants, and other trained professionals directly involved with PLHIV and/or with those most directly affected by the infection 19.

Another challenge is acknowledging, respecting, and promoting the right of adolescents and young people (whether they are living with HIV and AIDS or not) to high-quality information and education on topics related to sexuality and reproduction, and to access to SRH services and to family planning (FP) materials, including those related to assisted reproduction. Where adolescents and young people living with HIV have opportunities to live together and socialize, they invariably express a wish that more time could be devoted to care and assistance. Their idea of quality care is defined as synonymous with having health workers who are qualified to listen to them or converse with them about issues related to their personal development, sexuality, and reproduction (conception and contraception)^{20, 21}.

Paiva, Vera e cols. Sexualidade de mulheres vivendo com HIV E AIDS em São Paulo, em http://www.scielo.br/pdf/csp/v18n6/13257.pdf , accessed September 9, 2008.

EngenderHealth/UNFPA, Sexual and Reproductive Health Needs of Women and Adolescent Girls living with HIV, Research Report for Qualitative Findings from Brazil, Ethiopia and the Ukraine, Brazil/Ethiopia/Ukraine, 2006, Available at: www.unfpa.org/upload/lib_pub_file/619_filename_SHRH-of-hiv-positive-women.pdf, accessed April 1 2007

^{21.} Ayres, J.R. et al., Adolescentes e jovens vivendo com HIV E AIDS: cuidado e promoção da saúde no cotidiano da equipe multiprofissional, São Paulo, Office Editora e Publicidade, 2004 (Aids Novos Horizontes).

How we arrived at this publication

During the period 2004 to 2008, EngenderHealth, in a partnership with the United Nations Population Fund (UNFPA) and the David & Lucile Packard Foundation, engaged in a number of activities with program planners, health workers, representatives of civil society, and activists, including:

- Reviewing all national and international literature on SRH programs and projects and on human rights that had any relation to women and adolescent girls living with HIV
- Holding technical meetings to discuss a guide on the sexual and reproductive health needs of women living with HIV and AIDS
- Holding an Electronic Discussion
 Forum in 2006, with the
 participation of health workers,
 human rights specialists, activists,
 and women living with HIV from a
 number of different countries
- Analyzing the content of Brazilian laws and policies related to SRH and HIV and AIDS over the past 25 years
- :: Conducting focus groups composed of women, adolescent girls, and their male partners living with HIV
- Conducting in-depth interviews with managers/administrators,

- health workers and educational professionals, representatives of governmental bodies, and representatives of civil society organizations committed to the sexual rights and reproductive rights of women and adolescent girls living with HIV
- representatives of the National
 HIV and AIDS Programme, and
 representatives of the Technical
 Area for Women's Health of the
 Ministry of Health
- Publishing Sexual and Reproductive Health of Women and Adolescent Girls Living with HIV and AIDS: A Manual for Program Managers and Trainers

"Establishing Intervention Priorities of the Program to Link Actions in SRH and in HIV and AIDS," which was directed at health workers, representatives of municipalities and states, and groups of women living with HIV and AIDS from the municipality of Niteroi in the state of Rio de Janeiro

Already, in 2006, on the occasion of the first consultative meeting with strategic stakeholders, the intention of EngenderHealth and the partners was to join forces in promoting the rights of PLHIV in Brazil by means of a publication; with the launching of the Integral Plan for Confronting the Feminization of AIDS and other STDs by the Brazilian government in March 2007, such a publication became even more opportune.

In that regard, the representatives of the institutions, organizations, and networks that participated in the second consultative meeting held at the UNFPA offices in Brazil on February 14 and 15, 2008²², agreed that from then on, the publication would be called Sexual Health and Reproductive Health of Women and Adolescent Girls Living with HIV: Guidance for Health Managers, Health Workers, and Activists, and that it would aim to meet the following objectives:

- Provide supporting elements for making the Integral Plan for Confronting the Feminization of AIDS and other STDs operational;
- 2 Contribute to improving the SRH care that should be made available to adult women and adolescent girls living with HIV;
- 3 Contribute to a transformation of the values that determine policies, programs, and actions in the field of sexual rights and reproductive rights, by helping activists influence political decision making and the allocation of funds and resources

^{22.} UNFPA; EngenderHealth; UNAIDS; National STD and AIDS Program of the Health Surveillance Department, Ministry of Health; Department of Policies for Women; Department of Programmatic and Strategic Actions of the Health Care Department, Ministry of Health; Technical Area for Women's Health - Health Care Department of the Ministry of Health; Technical Area for Adolescent and Young People's Health - Health Care Department of the Ministry of Health; Inter-sector Commission for Accompanying Policies on STD and AIDS of the Brazilian National Health Council; ECOS; CEDAPS; National Movement of PositHIVe Women Citizens; Brazilian Chapter of the International Community of Women Living with HIV/AIDS- ICW Brasil; GAPA; GESTOS; Indigenous Nucleus of Positive Women Citizens; São Paulo University.

4 Transform the perceptions of society and community support in the defense and promotion of the rights of PLHIV, with an emphasis on sexual and reproductive rights (advocacy)²².

^{22.} Advocacy should express values or ideas that support the defense and promotion of a new society in which differences are not used as excuses for exclusion or oppression and issues of power between men and women do not lead to discrimination and inequality. http://www.anis.org.br/oficinas/visualizar_oficina.cfm?ldOficina=2, site consulted on August 29, 2008.

KEY CONCEPTS IN SRH

Health consists of a set of integrated, collective conditions influenced by a vast number of political, socioeconomic, cultural, environmental, and biological factors. For a long time, it has been known that illness and health, far from being either random or predestined events, are in fact historical and social processes defined by a society's mode of living and its means of organizing itself. That being so, health as a fundamental right can only come about if certain basic principles are observed, such as: nondiscrimination and nonviolence; freedom of sexual orientation, sexual identity, and gender expression; the freedom and autonomy of men and women in regard to their own bodies, at every stage of their lives; access to accurate information couched in clear language; access to good-quality formal education; food and nutrition security; safe, healthy surroundings and decent housing; decent work and employment; security; and all dimensions of development.

Reproductive health is that state of physical, mental, and social well-being in all aspects related to the reproductive system, its functions, and its processes. Reproductive health involves an individual's being able to enjoy a satisfactory sexual life without risks and being free to decide whether or not to have children, how many children to have, and at what time of life to do so.

Sexual health means the ability of men and women to enjoy and express their sexuality without being threatened by STDs or unwanted pregnancies and being free from violence and discrimination.

Among other things, putting into effect the right to sexual health and reproductive health presupposes the following rights:

- :: The right of men and women to autonomy over their own bodies (a fundamental aspect of health at all stages of life)
- The right of men and women to express and enjoy their sexuality without being threatened by STDs, unwanted pregnancies, coercion, violence, or discrimination
- :: The right to mutual respect in sexual relations
- :: The right to enjoy a safe and pleasant sex life founded on self-esteem
- The right to value life, personal relations, and the expression of each person's individual identity
- The right of access to the means of the pleasurable, safe, and healthy exercise of sexuality and reproduction, free from discrimination, coercion, or violence
- The right to make free, responsible decisions as to the number of children to have, the intervals between them, and the feasibility of having them, with the equal involvement of both partners
- :: The right of access to accurate information appropriate to differing realities and needs
- The right of universal access to contraceptive methods
- The right of access to new technologies and methods of assisted reproduction that guarantee people's freedom of choice and do not put their health or their lives at risk

2 General Recommendations

Adult women and adolescent girls living with HIV, in the same way as men of all ages, have the right to integrality and equality in health care. In regard to SRH-related issues, there is a need to ensure access to accurate information transmitted in a language that is accessible and adapted to different realities and necessities; to services, materials, and technologies; and to good-quality services and practices capable of effecting solutions.

The statements and narratives of women and adolescent girls with HIV that have been gathered in the various national surveys and collected in other less formal contexts enable us to discern situations in which the sexual rights and the reproductive rights of some populations are still being violated. An example is in the difficulty that PLHIV have in talking to health workers about exercising their sexuality, their wish to have children, assisted reproduction, prevention of vertical transmission of HIV and

syphilis and the prevention of other STDs²⁴, and transmission of HIV to partners, among other issues²⁵.

Accordingly, the primary targets of the recommendations put forward in this document are health managers, health workers, and activists working to protect, promote, and defend the rights of PLHIV, especially rights associated with the SRH of women and adolescent girls living with HIV and AIDS. The reference framework has been based on human rights and a concept of vulnerability that encompasses its individual, social/ contextual, and political/programmatic (institutional) aspects, as described by Mann and Tarantola (1996)²⁶ and Ayres and their collaborators (2005 and $2006)^{27, 28}$.

In regard to the individual dimension of vulnerability, an analysis was made of the contexts that make women and adolescent girls living with HIV vulnerable to reinfection or falling sick with AIDS; their resources, strategies,

^{23.} It should be pointed out that STDs may manifest themselves in atypical ways in PLHIV, especially in the case of pregnant women, and that makes diagnosis difficult and heightens the risk of treatment failure.

Translated of CZELUSTA, A.; YEN-MOORE, A; VAN DER STRATEN, M.; CARRASCO, D.; TYRING, S. K. An
overview of sexually transmitted diseases. Part III. Sexually transmitted diseases in HIV-infected patients. J Am
Acad Dermatol 2000, 43(3):409–436.

MANN, J. M. e TARANTOLA, D. From Vulnerability to Human Rights. In: MANN, J. M. e TARANTOLA, D. (eds.).
 AIDS in the world II: the Global AIDS Policy Coalition. Oxford: Oxford University Press, 1996.

^{26.} AYRES, J. R. C. M. et al. O conceito de vulnerabilidade e as práticas de saúde: novas perspectivas e desafios. In: CZERESNIA, D. e FREITAS, C. M. (orgs.). Promoção da saúde: conceitos, reflexões, tendências. 3.ed. Rio de Janeiro: Fiocruz, 2005, p. 117–140.

AYRES, J. R. C. M. et al. Risco, vulnerabilidade e práticas de prevenção e promoção da saúde. In: CAMPOS, G. W. S. et al (orgs.). Tratado de Saúde Coletiva. São Paulo; Rio de Janeiro: Hucitec; Fiocruz, 2006, p. 375–417.

and potentialities in the field of primary and secondary prevention; access to good-quality services and to actions, materials, and technologies associated with sexual health and reproductive health; and abundant, accurate information couched in accessible language on fundamental rights, especially sexual rights and reproductive rights.

Regarding social vulnerability, the aspects examined were those related to freedom of expression for women and adolescent girls living with HIV and AIDS, in the promotion and defense of their rights; in the formulation, monitoring, and evaluation of public policies; and their access to means of communication and information. Apart from considering the presence of HIV in their bodies and the consequences of that, a series of other factors may affect the living conditions and health of these and other women (individually or collectively), such as gender relations, class, age, race, color of skin or ethnic group, sexual orientation, sexual identity, expression of gender, religious faith, lifestyle, incarceration, and temporary or permanent disability, in addition to issues related to violence, stigma, discrimination, and inequality.

Finally, in the programmatic or institutional dimension of vulnerability,

the aspects addressed were those related to: the political commitment of the authorities to formulate. implement, monitor, and evaluate public policies directed at fostering equality and not discrimination; the protection and promotion of the rights of women, children, adolescents, and young people; the organization of services so that they can address the needs of PLHIV and face up to the feminization of the epidemics of HIV and other STD; and the formulation, implementation, monitoring, and evaluation of integrated services for promoting SRH, preventing disease, and providing care and treatment for STDs and HIV and AIDS and support for PLHIV.

Similar importance was attributed to the commitment and efficacy of the health sector in coordinating with other sectors, especially those of policies for women, policies for youth, education, culture, communication, human rights, and social development, and with organized civil society and social movements.

Although all of the recommendations are interrelated, for the sake of clarity they have been separated into the following four distinct areas:

1 Create an environment fostering respect, protection, and promotion

of the sexual and reproductive rights of women and adolescent girls living with HIV and AIDS.

- 2 Strengthen the health system to improve the availability of comprehensive programs and activities promoting sexual and reproductive health care for women and adolescent girls living with HIV and AIDS.
- 3 Ensure the meaningful participation of women and adolescent girls living with HIV and AIDS in the formulation, monitoring, and evaluation of public policies and in the promotion and defense of their rights.
- 4 Strengthen intersectoral activities that support decision making by adolescent girls and young women living with HIV and AIDS in regard to their personal development, sexuality, and reproductive choices.

... nowhere in the world is there anyone, or is there any kind of magic capable of guaranteeing to any woman whatsoever who becomes a mother, that she will have a life span long enough to raise her children.

Women die because they are "mortal" beings, whether they have children or not, and that situation is no different and cannot possibly be seen to be any different for women living with HIV...

Some women die, others don't. That has to do with serostatus, age, social class, and so on... but especially because there are thousands of possible "causes of death" apart from AIDS. Who can auarantee to a mother or a father that they will be able to raise their children until the time when they no longer have need of their parents? It is absurd to try and equate the right to maternity with death. Isn't it true that every one of us is "mortal," irrespective of any

44-year-old woman living with HIV, two sons²⁹

HIV considerations?

Create an environment fostering respect, protection, and promotion of the sexual and reproductive rights of women and adolescent girls living with HIV and AIDS.

Recommendations:

- :: Guarantee that the Integral Plans for Confronting the Epidemics of HIV and Other STD in the states, municipalities, and the Federal District take local realities and necessities into account. including the diversity of the female population in regard to age-group, sexual orientation, disabilities, ethnic and cultural origins, religious persuasion, lifestyle (including drug use and alcohol consumption), and place of residence—in the country, in forest areas, in quilombos or in urban areas, and including those who live on the streets—as well as those specific to adult women who are in prison or adolescent girls who have been deprived of their liberty.
- **::** Guarantee that the Integral Plan for Confronting the Feminization

- of the Epidemics of HIV and
 Other STD is put into operation
 in the states, municipalities, and
 the Federal District, with special
 attention to those initiatives directed
 at linking SRH and HIV promotion
 and care, primary and secondary
 prevention, care and treatment for
 STD/HIV, and actions that involve
 public policies for women, youth,
 education, culture, justice, social
 development, work, employment,
 and income generation.
- :: Guarantee the adoption of a cross-disciplinary, equitable approach to SRH care for women and adolescent girls living with HIV and AIDS that includes access to accurate information couched in suitable language, access to SRH care, including prevention of

^{29.} Statement from Silvia Almeida, given for the article From Shock to Action, available at http://www.engenderhealth.org/our-work/success-stories/brazil-hiv-activist-demands-rights.php, site accessed September 9, 2008

- cervical cancer, viral hepatitis, and STDs; interruption of pregnancy (in those situations called for in the legislation³⁰ in force); and the provision of humane, integrated care for those who are in situations of high-risk abortion or who are victims of violence; and FP, including assisted reproduction and emergency contraception.
- Ensure the participation of women and adolescent girls living with HIV and AIDS in the planning, implementation, monitoring, and evaluation stages of National Policies on Integral Health Care for Women and on Integral Health Care for Adolescents and Young
- People in the three spheres of administration of the Unified Health System – SUS, as well as in the Integral Plan for Confronting the Feminization of the Epidemics of HIV and other STD in the three spheres of government.
- Promote studies, research, surveys, or initiatives that seek to identify and address those symbolic and material factors that have a negative influence on the quality of health services directed at women and adolescent girls living with HIV and AIDS, with a view to improving policies, programs, plans, and/or services in the states, municipalities, and the Federal District.

^{30.} Contemplated specifically in the Brazilian Penal Code since 1940, induced abortion is only not considered to be a crime in Brazil when it is associated with cases of rape or when the woman's life is endangered. http://www.datasus.gov.br/cns/temas/tribuna/regaborto.htm site accessed on September 16, 2008.

Strengthen the health system to improve the availability of comprehensive programs and activities promoting sexual and reproductive health care for women and adolescent girls living with HIV and AIDS.

I do not think that women's rights are fully respected yet. And there are not many people who worry about the sexual health and reproductive health of women living with HIV and AIDS, either. They are all much more worried about making sure that mother-to-child transmission doesn't take place.

Health Worker³¹

Recommendations:

- II Integrate into the curricula of graduate courses in human sciences and health sciences the themes of human rights, sexual rights, reproductive rights, ethnic/racial relations, gender relations, and diversity, in addition to questions related to overcoming stigma and discrimination associated with living with HIV and AIDS.
- "social determinants of health conditions"³² in all permanent education activities for health workers, including community health agents³³, and ensure that among other factors, the correlation
- between the process leading to poor health and socioeconomic, regional, ethnic, racial, gender, and age-related disparities and other factors (like gender violence against women, stigma and discrimination associated with living with HIV, and other human rights violations) are strongly highlighted, as well as the impact of such correlations on the quality of the care being provided.
- :: Guarantee that the themes of human rights and living with HIV and AIDS and rights are addressed in the programs of permanent education and ongoing training for health workers and community

^{31.} Statement given for the research Sexual and Reproductive Health Needs of Women and Adolescent Girls living with HIV, Research Report for Qualitative Findings from Brazil, Ethiopia and the Ukraine, Brazil/Ethiopia/Ukraine, EngenderHealth e UNFPA, 2006.

^{32.} The social determinants of health include the more general socioeconomic, cultural, and environmental conditions of a society, and relate to the living and working conditions of its members, such as housing, sanitation, work environment and health and education services and also include the fabric of social and community networks. http://www.determinantes.fiocruz.br/chamada_home.htm. Accessed on October 30, 2008.

^{33.} The Community Health Agent is expected to carry out work in the field of disease prevention and health promotion through actions carried out at the level of the households or the community which may be individual or collective and are developed and unfolded in obedience to the directives of the Unified Health System – SUS and under the supervision of municipal, state, regional or federal manager. http://www.trt02.gov.br/geral/tribunal2/Legis/CLT/Profis regul/L11350 06.html> accessed on September, 18, 2008.

- health agents—above all, for those who work in primary health services and specialized services for STD and AIDS who collaborate with PLHIV in the process.
- Broaden opportunities to update health workers' knowledge about and skills on the SRH of HIV-positive women and girls through training and certification on sexual rights and reproductive rights, family planning, and scientifically acceptable reproductive technologies.
- Review and revise work norms and processes, with a view toward adapting actions and programs to the differing needs and realities of women and adolescent girls living with HIV and AIDS in questions related to integrated care in SRH and care in situations of sexual, intrafamily, or domestic violence, in accordance with Ministry of Health directives and with the legal provisions of Law No. 11.340/2006 (Maria da Penha Law)³⁴.
- and HIV programs and the linking of actions directed at prevention of HIV, viral hepatitis, and STDs; prevention of reinfection; diagnosis and management of viral hepatitis and STDs and AIDS; prevention of unintended pregnancies; and support for PLHIV, including the promotion of SRH and health care in the three spheres of administration of the Unified Health System.
- :: Create opportunities for sharing and exchanging experiences and lessons learned in the promotion, defense, and enforcement of the rights of PLHIV, including their sexual rights and reproductive rights, and involve health managers and health workers in the sharing process, as well as workers from the fields of education, policies for women, policies for youth, labor, employment, and income, and people from the women's movement, the movement to combat AIDS, the academic community, and other strategic personnel.

Access to a gynecologist, especially needful for women with the virus, was directly associated with the level of knowledge on preventing motherto-child transmission that we found and was lower than it should be among the women and even lower among the men. (...) Almost half the women did not understand the meaning of the results of the laboratory tests that periodically monitored their state of health. Health Workers³⁵

^{34.} This law establishes mechanisms to curb domestic and family violence against women in keeping with subheading § 8 of Article 226 of the Federal Constitution and the Convention on the Elimination of All forms of Discrimination against Women and the Inter-American Convention to Prevent, Punish and Eradicate Violence against Women: sets out provisions on the setting up of special magistrates courts to handle Domestic and family Violence against Women; alters the Penal Process Code, the Penal Code and the Law of Penal Execution and other provisions. www.planalto.gov.br/ccivil/_Ato2004-2006/2006/Lei/L11340.htm

^{35.} Segurado, A. C.; Miranda, S. D.; Latorre, M. and the Brazilian Enhancing Care Initiative Team, 2003. Evaluation of care of women living with HIV and AIDS in the State of São Paulo. AIDS Patient Care and STDs, 17(2):85–93.

- investigation of the impacts of ARV therapy on the quality of health and the quality of life of women and adolescent girls living with HIV and AIDS, including aspects related to mental health, lipodystrophy, hormonal disturbances, menopause, loss of libido, and chronic-degenerative deficiencies and diseases stemming from AIDS.
- ## Foster research into co-infections and their impact on the quality of health and the quality of life of women and adolescent girls living with HIV and AIDS, including such infections as syphilis, human papillomavirus, herpes, cervical cancer, viral hepatitis, tuberculosis, and others, thereby contributing to the improvement of policies, programs, plans, and/or actions in the states, municipalities, and the Federal District.
- Guarantee the development of strategies to broaden participation and engagement of the male partners of women and adolescent

- girls living with HIV and AIDS, particularly in counseling on sexuality, positive prevention, family planning and reproductive health, prevention of mother-to-child transmission of HIV, prevention of syphilis, and prevention of gender violence directed at women.
- Reinforce actions directed at promoting the SRH and rights of indigenous and Quilombola³⁶ women and adolescent girls, of those with disabilities, and of those living on the streets or in prison especially those living with HIV and AIDS), by guaranteeing the allotment of specific human, financial, and budgetary resources.
- Within the sphere of the Plan for Confronting the Feminization of the Epidemics of AIDS and other STDs, strengthen existing partnerships with other sectors of government, especially polices for women, youth, education, justice, social welfare, social development, labor, employment, and income generation, and those with organized civil society.

^{35.} Quilombola populations are understood to be those communities that resulted from the purchase and occupation of lands by former slaves; the peaceful occupation by former slaves of lands abandoned by their former owners during periods of economic crisis; or communities resulting from the occupation of lands donated to patron saint cults. Historically, Quilombola lands are in areas that are difficult to access and the communities have a background of resistance to domination, and in fact incorporate the living memorial of Afro-Brazilian history. Sites consulted: http://www.koinonia.org.br/oq/quilombo.asp and http://bvsms.saude.gov.br/bvs/publicacoes/brasilquilombola_2004.pdf

- Within the sphere of the Plan for Confronting the Feminization of the Epidemics of AIDS and other STDs, develop communications and information strategies to promote the rights of PLHIV, especially their sexual rights and reproductive rights and the prevention of vertical transmission of HIV and syphilis, among others, by guaranteeing the broad dissemination of communications products directed at health workers, health managers, health service users, and society at large.
- Widely disseminate the booklets Users' Rights and Health Service Users among women and adolescent girls living with HIV.
- ** Qualify professional staff in technical and administrative areas to collect and register SRH information, with special attention to variables that are usually attributed little importance, such as race, color, and ethnic group³⁷, occupation, level of schooling, sexual orientation, and gender identity, and sensitize professional

- staff to the need for such information to be registered on the basis of the service user's own declaration.
- :: Use the question of race or color when producing SRH statistics at its intersection with other variables, such as sex, age, occupation, level of schooling, place of residence, sexual orientation, and disabilities, with a view to: identifying needs and demands, defining priorities, allocating resources, and promoting changes in work processes according to the directives of the National Health Plan and the National Policy for Integral Health Care for the Negro Population and contributing to perfecting of the Integral Plans for Confronting the Epidemics of HIV and other STD in the states, municipalities, and the Federal District.
- Raise the awareness of technical and administrative staff and health service users regarding the importance of users' self-declaration of race, color, or ethnicity.

^{37.} In most of the services, information on race, color, or ethnicity is collected by observation. That means that an employee of the service fills in a form and defines the user's race, color, or ethnicity based on personal judgment, without consulting the service user (which is described as "hetero-classification"). Ideally, the service user would state his or her race, color, or ethnicity according to the categories adopted by the IBGE (black, mixed, oriental, white, and indigenous). See: Goulart, F. A., and Tannús, L. 2007. Subsídios para o enfrentamento de racismo na saúde, Brasília: DFID; accessed at: www.combateaoracismoinstitucional.com/images/padf/subsidios.pdf, July 20, 2008.

- **::** Establish indicators for monitoring the progress of integrating SRH and HIV services, and define mechanisms and strategies for evaluating the results and impacts together with the different groups of women themselves.
- ELHIV, especially women and adolescent girls, in the formulation, monitoring, and evaluation of policies, actions plans, or programs for the promotion, defense, or enforcement of their rights.

Ensure the meaningful participation of women and adolescent girls living with HIV and AIDS in the formulation, monitoring, and evaluation of public policies and in the promotion and defense of their rights

Recommendations:

- Strengthen the participation of women and adolescent girls living with HIV and AIDS as political participants in the development and achievement of economic and social autonomy, in freedom of expression, and in the power of decision in regard to their own lives and their own bodies.
- Foster and encourage qualification and permanent education processes for monitoring, and evaluation of public policies for PLHIV, especially women and adolescent girls.
- Expand and invigorate the participation of PLHIV, especially women and adolescent girls (by means of councils, networks, committees, and other), in the formulation, monitoring, and evaluation of policies, plans,

- programs, actions, and goals of national, state, and municipal programs, particularly those in the fields of health; education; women, youth, children, and adolescents; and work, employment, and income.
- Document, systematize, and disseminate the lessons learned and good practices in the promotion, defense, and protection of the rights of PLHIV, especially sexual rights and reproductive rights, from a gender and life-cycle perspective.
- Stimulate and foster civil society initiatives to develop communications strategies and the production and dissemination of audiovisual materials, materials for radio and television, printed matter, and electronic media products adapted to the differing

I feel a sense of gratitude for being in the right place at the right time and being able to witness a transformation that takes place over time. I feel proud of myself and my origins for not having given up on the commitment I made to myself: that of not succumbing emotionally; of getting access to information and contact with the women's movement and the movement of women living with HIV/AIDS: for having made myself available and made the effort to ensure that my personal experience could serve other people as a form of information and knowledge.

52-year-old woman living with HIV/AIDS³⁸

How social control is exercised in the Unified Health System - SUS

("Social control" is a Brazilian term used to designate the democratic instruments and processes available to civil society to intervene in the application of policies at any stage, from the moment of their formulation up to the stage of their execution.)

Health councils are the formulators and inspectors of health policies. They are instruments that make it possible, in a democratic manner, to expand decision-making capacity and to broaden participation in the management of and collective responsibility for the consolidation of the SUS. Their legal institution in the federal, state, and municipal spheres of authority determined that in their composition service users, health professionals, and health service providers should be equally represented. The health councils are deliberative bodies, and within them, government plays the role of an integral member, along with the representatives of the other segments.

Health conferences are periodic public events whose main purpose is to define general guidelines for health policy. They are organized by the federal, state, and municipal health councils and function as forums where service users, health workers, and others can discuss major health issues such as management, funding, and human resources. These participatory bodies deliberate on the steps to be taken to advance and consolidate the SUS.

There are other channels for the participation of civil society, especially in monitoring actions and activities, such as the Services Management Councils, the District Health Councils, the Maternal Mortality Committees, and the Monitoring Committees of the National Pact for the Reduction of Maternal and Neonatal Mortality.

Further information can be found at: http://conselho.saude.gov.br/.

RECOMMENDATIONS

realities and needs of the target audience and aimed at raising awareness about the feminization of the epidemics of AIDS and other STDs, about positive prevention, about the rights of PLHIV (including their sexual rights and reproductive rights), about facing up to stigma, discrimination, and violence, and about other relevant themes.

Strengthen intersectoral activities that actively support decision making by adolescent girls and young women living with HIV and AIDS in regard to their personal development, sexuality, and reproductive choices.

Recommendations:

- Organize health and social services in such a way that they attract young people by offering them a welcoming, friendly atmosphere and the possibility to construct shared solidarity, and offer services committed to promoting the health, sexual and reproductive rights, and participation of young people in a respectful manner.
- ## Train and certify staff in health, education, and other areas to work with adolescents and young people, by adopting democratic and respectful postures that take into consideration the needs and expectations of those living with HIV and AIDS, that respect their values, acquired knowledge and life's experiences, and their right

- to privacy and confidentiality, that promote their autonomy and emancipation, and that encourage them to reflect on and define their own life projects.
- Reaffirm the strategic role of lower and higher secondary education institutions as strategic locales for articulating actions to promote, protect, and put into effect the sexual rights and reproductive rights of young people and adolescents, including those living with HIV and AIDS, by means of the Health and Prevention in Schools (SPE) Project³⁹.
- Within the sphere of the SPE Project, strengthen the Plan for Confronting the Epidemics of

There could be a space for the young people to get together. It would be nice if all the doctors were to make all appointments for young people on the same day. That way, they could be together and talk over many different things while they were waiting for others to be attended to... It could be done so that there was a psychologist present and some young people who were wellinformed about certain situations. So together, they could suggest movies to watch, theater activities, art activities... that way it would be more light-hearted, so we could talk about the things that bother us. Never being super-protective nor blaming anyone excessively, but rather, exchanging experiences, because just as a trainer can teach people, he can also learn from them. There could be a kind of capacity building for young people to enable them to speak in front of everybody in the places we go for treatment; speak about what HIV is, how it behaves inside our bodies, and about the fact that we are merely living with the virus, we ourselves are not the virus.

21-year-old young woman living with HIV/AIDS⁴⁰

^{39.} The Health and Prevention in Schools (SPE) Project is a joint initiative of the Ministry of Education and the Ministry of Health, in partnership with UNESCO, UNICEF, and UNFPA. The project seeks to promote integrated health and educational actions through an intra-governmental approach, with the purpose of reducing young people's and adolescents' vulnerability to STD and HIV infection, to AIDS, and to teenage pregnancy.

^{40.} Statement given by a young woman activist from Incentives to Live Group (GIV).

HIV and other STD and of the National Plan of Policies for Youth; strengthen activities in permanent and integrated education for health workers and workers in the fields of human rights, sexuality, and education about drugs and HIV and STD infection or falling sick with AIDS; and guarantee the participation of adolescents and young people to facilitate the process, including those with permanent or temporary disabilities and those living with HIV and AIDS.

- ** Facilitate access to counseling services addressing SRH, use of alcohol and drugs, and prevention of HIV and AIDS among adolescents and young people undergoing social rehabilitation processes in correctional institutions, in harmony with inter-ministerial instructions no. 1426/2004 and no. 340/2004.
- Stimulate the establishment of intersectoral partnerships across the health sector, educational institutions, cultural organizations, organized civil society, and the sectors responsible for youth and adolescents with legal problems, who are incarcerated, or who are

- living in the streets, in order to carry out activities and programs of integrated care (psychosocial support, FP counseling, and positive prevention and care and treatment) for women and adolescent girls living with HIV and AIDS.
- Estimulate and foster integrated, permanent training for professionals responsible for the care, education, culture, leisure, sport, and the promotion and protection of the rights of adolescents and young people with legal problems, who are incarcerated, or who are living in the streets, with a view to incorporating SRH care and/or counseling and the prevention of gender-based violence into their current professional responsibilities.
- ## Promote permanent education and qualification in human rights, including sexual rights and reproductive rights and the prevention of gender-based violence, for young people and adolescents, using peer education methodologies, regardless of whether they are in school or out of it, or in institutions for young people and adolescents with legal problems or who are living in the streets.

- Stimulate and support the participation of adolescents and young people living with HIV and AIDS in the monitoring and evaluating of public policies and advocate for their rights, including their sexual rights and reproductive rights.
- ## Promote, and provide technical and financial support for, meetings of adolescents and young people living with HIV and AIDS, to help them share their experiences in positive prevention and in advocacy on sexual rights and reproductive rights, by means of partnership arrangements with youth networks and organizations and with international and governmental bodies.
- Invest in strengthening the economic independence of adolescent boys and girls and young men and women living with

- HIV and AIDS, by broadening their future prospects, including providing access to accurate information, couched in adequate language; formal education; culture; leisure; professional orientation; the employment market; microcredit programs; and human rights education.
- # Provide technical and financial support for the initiatives of organizations, groups, and networks of adolescents and young people living with HIV and AIDS for the development of communications products (for example, audiovisual materials, materials for radio and television, printed matter, and electronic media) addressing rights issues, including sexual rights and reproductive rights and positive prevention, through partnerships between the government and international organizations and other strategic actors.

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Appendixes

Reference documents used for creating this guidance

This document has been organized around and based on the principles and directives of the Unified Health System (SUS), Brazilian legislation, public policies, plans and programmes now in place, international rights conventions, agreements, treaties and pacts ratified by the Brazilian State, and action plans originating from various international conferences to which Brazil is a signatory. They have all been set out in the following list:

Universal Declaration of Human Rights. 1948.

The document proclaims the common ideal to be attained by all peoples and all nations with the aim of enabling every individual and every body of society, with the Declaration in mind, to make efforts by means of education, to promote respect for those rights and liberties and the adoption of progressive national and international measures to ensure universal recognition and effective observance of them, not only among the peoples of the Member States themselves, but among the peoples of the territories under their jurisdiction.

International Convention on the Elimination of All Forms of Racial Discrimination, 1965.

The convention promotes and encourages universal and effective respect for human rights and fundamental liberties for all without discrimination based on race, sex, language or religion.

International Covenant on Civil and Political Rights, 1966.

The first document to establish legal links between Human Rights and Economic, Social and Cultural Rights.

International Covenant on Economic, Social and Cultural Rights, 1968.

This pact favors the implementation of the provisions of the Universal Declaration of Human Rights and determines that Signatory States shall be held responsible internationally for any violations of those rights, including the rights to work and receive fair pay, the right to form and belong to labor unions, the right to attain an adequate standard of living, the right to an education, the right of children not to be exploited, and the right to participate in the cultural life of the community.

The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), 1979.

In this document, UN membercountries manifest their special concern with the fact that in conditions of poverty, women have minimum access to food, health, education, capacity building, or job opportunities, as well as having other needs that are not met.

International Convention on the Rights of the Child, 1989.

The Treaty was created for the protection of children, classifying children as - all human beings under the age of 18 except when the legislation concerning children defines coming of age at a lower figure.

Vienna Declaration and Programme of Action, 1993.

This reaffirms the commitment of UN member-countries to the universal nature, indivisibility and inter-relatedness of Human Rights.

International Conference on Population and Development, 1994.

Also known as the Cairo Conference, it promoted a change in the paradigm used to address the themes of population and development. Prior to the Cairo Conference, the population agenda was oriented by demographic considerations, population control,

and family planning in the strictest sense; after it, the focus was shifted to the promotion of human rights, with an emphasis on the exercise of sexual rights.

The Inter-American Convention on the Prevention, Punishment, and Eradication of Violence Against Women, 1994.

Known as the "Convention of Belém do Pará", it represents a considerable step forward at the regional level, insofar as it presents, defines, and measures the dimensions of violence against women and recommends governments in the Americas to take measures to prevent, punish, and eradicate that kind of violence.

Beijing Declaration Platform for Action of the 4th World Conference on Women, 1995.

Documents that represent the ratification of commitments previously made by UN member-states and also consolidate a global understanding in regard to the Human Rights of Women offering a base on which to construct public policies for addressing the problem of inequalities between men and women.

United Nations Millennium Declaration, 2000.

In this document, the UN set out what it considered to be the priority

problems to be addressed to overcome inequalities in all parts of the world. Based on this document, the UN system established eight major development goals to be achieved by 2015, among which are the reduction of poverty, the promotion of equality of the sexes and the autonomy of women, the fight against HIV, AIDS, malaria, and tuberculosis, the promotion of maternal health, and universal access to sexual and reproductive health.

Declaration and Action Plan of the 3rd World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance, 2001.

These documents ratify commitments made to the proposals and principals set out in the United Nations Charter and the Universal Declaration of Human Rights and establish a common platform for creating public policies to address the issues of ethnic-racial inequality and recognize the specificities of women.

Positive Prevention: prevention strategies for people living with HIV, 2004

This report elaborated in the United Kingdom by the Parliamentary Group on Population, Development and Reproductive Health made it possible for the International HIV/ AIDS Alliance to publish a document emphasizing the need for a care offer in the health services that integrates SHRH and HIV

Convention on the Rights of Persons with Disabilities, 2006.

The convention promotes, protects, and guarantees the full and equal enjoyment of all human rights and fundamental liberties by persons with disabilities and promotes respect for the inherent dignity of all people with disabilities.

Ibero-American Convention on the Rights of Young People, 2008.

This recognizes the rights of young people to fully enjoy all human rights whether civil, political, social, economic or cultural.

The New York Commitment: Integrating HIV and AIDS and Sexual and Reproductive Health, 2004.

This document was elaborated after a consultative meeting organized by UNFPA and UNAIDS, in a partnership with Family Care International in New York and it argues in favor of observing the connection between the epidemic of HIV and AIDS and the central issues in the debate on sexual health and reproductive health, given that the majority of HIV infections occurs via sexual relations or associated to pregnancy, birth and breast feeding.

Glion Call to Action on Family Planning and HIV/AIDS Prevention for Women and Children, 2006.

This call to action took part in Switzerland and reinforced the need to link together reproductive planning and the prevention of mother-to-child transmission. The Call was made as part of the actions and objectives proposed by the International Conference on Population and Development.

High-Level Global Partners Forum— Call to Action: Towards an HIV-free and AIDS-free Generation, 2005.

The forum was held in Abuja (Nigeria) with representatives of governments, multi-lateral agencies, partners, research institutions, civil society and persons living with HIV and AIDS and it emphasized that programs for prevention of vertical transmission with a wide outreach must include strategies to avoid transmission of HIV to women; offer services, and reproductive health actions and materials to women living with HIV; avoid transmission of HIV during pregnancy and birth and minimize the transmission of HIV by adopting safer practices for the children.

National Reference Frameworks

Brazilian Federal Constitution, 1988.

The constitution establishes fundamental rights and guarantees and recognizes the universal nature of the right to health, and the duty of the State to provide access to that right.

Declaration of the Fundamental Rights of People with the AIDS Virus, 1989.

Document elaborated and approved at the National Meeting of Non Governmental Organizations and held in the city of Porto Alegre in 1989. It establishes the priorities and sets out a group of principles that must be respected to ensure the rights of people living with HIV and AIDS.

Children and Adolescents Statute.

Law n° 8.069 dated July 13 1990 – guarantees the integral universal rights of children and adolescents. The statute declares that children and adolescents are subjects endowed with rights to be guaranteed, by the family, the community, society at large and the State. Access to actions and services promoting health protection and recovery is guaranteed by the Unified Health System.

Strategic Programme of Affirmative Actions: Negro Populations and AIDS, 2005.

Elaborated by a work group made up of representatives of the government and civil society with the aim of promoting actions that can provide elements of support to the development of policies addressing the epidemic, directed specifically at the Negro population.

Legal Framework: Health, the Right of Adolescents, 2006.

Identifies the major national and international documents regarding the legal provisions for the rights of adolescents to instruments of protection and mechanisms for controlling and monitoring compliance with their recognized rights, among other provisions.

Theoretical Reference Framework: Sexual Health and Reproductive Health of Adolescents and Young People, 2006.

Offers theoretical/political, regulatory and programmatic elements that can quide and support the implementation of actions directed at sexual health and reproductive health of adolescents and young people. It is especially relevant for SUS managers and administrators as well as other sectors of youth and adolescence-related public policies.

National Policy of Integral Health Care for Women – Principles and Directives – Ministry of Health, 2004.

This Policy published in 2004, was elaborated on the basis of the principles that guide the Integral Health Care for Women Program which was formulated in 1984. The Policy broadens the directives and strategies and widens the range of problems to be addressed in the sphere of integral health for women.

National Policy on Integral Health Care for the Negro Population (PSPN), 2006.

Approved by the National Health Council in November of 2006, the object of the PSPN is to promote the integral health of the Negro population setting priority on reducing ethnic/racial inequalities, combating racism and discrimination in the institutions and services of the SUS.

National Policy for the Promotion of Sexual and Reproductive Rights. Ministry of Health, 2005.

This policy has been elaborated by the Ministry of Health in a partnership with the Ministries of Education, Justice, Agrarian Development, Social Development and the Fight against Hunger, the Special Department of Policies for Promoting Racial Equality and the Special Department for Human Rights. The actions are structured along three lines associated to family planning,: expanding the offer of reversible (non surgical) contraception methods, improving access to voluntary (surgical) sterilization, and the introduction of assisted reproduction in the SUS.

Integral Plan for Confronting the Feminization of AIDS and other STDs, 2007.

The Plan is an inter-ministerial initiative involving the Special Department of Policies for Women and the Ministry of Health. Its purpose is to address the feminization of the epidemics of HIV and other STDs by means of integrated actions in the federal state and municipal spheres

involving government institutions, nongovernmental institutions and the social movements.

Operational Plan for the Reduction of Vertical Transmission of HIV/AIDS and Syphilis, 2007.

The goals of the plan are to expand the coverage of testing for HIV/ AIDS and Syphilis in antenatal care; increase the coverage of adequate treatment for pregnant women with syphilis including the provision of adequate treatment for their sexual partners; expand the coverage of vertical transmission prophylaxis against HIV/AIDS and syphilis in pregnant/parturient women and in exposed children.

2nd National Plan of Policies for Women - PNPM, 2008.

The 2nd PNPM is a government plan coordinated by the Special

Department of Policies for Women/ Presidency of the Republic. It was formulated with the extensive participation of civil society and approved at the 2nd National Conference on Policies for Women. The 2nd PNPM is based on the following principles: equality and respect for diversity; equity; autonomy of women; the secular nature of the State; universality of policies; social justice; transparency of administrative acts; and social participation and control. Among the 11 axes on which it is structured are Women's Health, and Sexual and Reproductive Rights and among its priorities it sets out: "stimulating the implantation and implementation of family planning assistance for men and women, adolescents and young people within the sphere of integral health care and respecting the principles of sexual and reproductive rights".





Fundo de População das Nações Unidas









do de População Nações Unidas



Partner Organizations















