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HIV and AIDS REPORTER: focus on women living with HIV 15 May 2007

produced by the [IDS Health and Development Information](#) team in collaboration with [Eldis](#) and the [DFID Health Resource Centre](#)

This is our monthly email bulletin, bringing together research to inform policy debates on health in developing countries.

The HIV and AIDS Reporter aims to provide readers with a more in-depth look at a particular area of health policy. This month's theme is **women living with HIV**. The bulletin also features summaries of new documents and other additions to the [HIV and AIDS Resource Guide](#).

HIV and AIDS Reporter archive - an archive is now available on the HIV and AIDS Resource Guide. See previous issues of the HIV and AIDS Reporter at <http://www.eldis.org/health/archive.htm>

All documents listed below are available free on the web. If you are unable to access any of these materials online and would like to receive a copy of a document as an email attachment, please contact i.young@ids.ac.uk.

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Feature: Women living with HIV

According to UNAIDS, there were 17.7 million women and girls living with HIV at the end of 2006 - an increase of over a million from 2004. With the expansion of access to anti-retroviral treatment (ART), people living with HIV and AIDS are now better able to live long, fulfilling lives than ever before. Yet women face many barriers, often rooted in gender inequalities, when it comes to accessing information, care, treatment and support for HIV. The result is that many women only seek help at the last minute when they are already very ill.

At the root of these barriers are the sexual double standards which mean that it is women who tend to be blamed for spreading HIV - by women as well as men - and may be labelled 'promiscuous' or 'vectors of disease'. This can lead to heightened levels of sexual and domestic violence, abandonment by families and communities, dismissal from employment, and loss of livelihood opportunities.

Fear of disclosing a positive HIV diagnosis for these reasons makes it difficult for women to access health services. Women's lack of decision-making power and constraints on their mobility in many contexts mean that they may have to ask their husband's permission to seek health care. This is especially difficult if they have not disclosed their HIV status. The costs of transport to clinics, coupled with the time lost from work or caring responsibilities, present further obstacles to women's ability to access treatment. These barriers are more severe for women than men because of women's unequal economic status which means that they are often financially dependent on men.

Stigma also makes it difficult for women and girls living with HIV to access information about safer sex. While HIV positive women may want sex and children just as much as anyone else, they often face criticism for being sexually active or are deemed irresponsible for wanting children. In some cases, women are forced into termination of pregnancy or sterilization by health workers. Young HIV-positive women experience particular hostility with regards to having children, encountering multiple criticisms on account of being female, young and pregnant, and HIV positive.

Despite these obstacles, women and girls living with HIV and AIDS have shown great resilience, determination and leadership in households and communities throughout the world. Networks of positive women have played a key role in advocating for improvements to treatment, care and support for women and girls living with HIV and AIDS. For example, in August 2005, the Argentinean branch of the International Community of Women Living with HIV/AIDS (ICW) supported two of its members to take the national Ministry of Health to court for failing to guarantee the quality of the AIDS drugs it distributes. They were successful!

ICW have called for governments and donors to invest in the capacity of networks and organisations run by and for positive women to participate meaningfully in the policy-making process. The expertise, insights, and accumulated experiences of women and girls living with HIV and AIDS can be a central force in tackling the epidemic, provided that others are prepared to listen and act on this knowledge.

Many thanks to Emily Esplen, [Bridge](#), for writing this feature and advising on content.

For more information see:

- The International Community of Women Living with HIV/AIDS
www.icw.org
- The Global Coalition on Women and AIDS
womenandaids.unaids.org/
- Siyanda focus on women and girls living with HIV and AIDS
www.siyanda.org/search/results_adv.cfm?Keywords=HIV07&Subject=0&Donor=0&Langu=E&StartRow=1

Recommended readings on women living with HIV

1. Women and girls living with HIV/AIDS: overview and annotated bibliography

Authors: E. Esplen
Bridge (2007)

HIV is both driven by and entrenches gender inequality, leaving women more vulnerable than men to its impact. This report - consisting of an overview, annotated bibliography, and contacts section - considers the specific challenges faced by women and girls who are living with HIV and AIDS. Women's social, economic, and legal disadvantage is exacerbated by a positive HIV status, and vice versa. Violations of women's social, economic, and legal rights in turn obstruct their ability to seek care, treatment and support, and to realise their sexual and reproductive health and rights (SRHR).

In many contexts, social and cultural values surrounding the importance of female purity mean that women and girls living with HIV and AIDS are also subject to greater discrimination than men. Sex workers, drug users, prisoners and migrants may face additional stigma. Women and girls living with HIV and AIDS are calling for recognition of their fundamental human rights, including their SRHR and the right to decide whether or not to have children; their meaningful involvement at all stages of the policy-making process; and government provision of accessible and equitable healthcare.

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC23849>

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2. HIV positive women and drug and alcohol use

Produced by: International Community of Women Living with HIV/AIDS (ICW) (2007)

Silent Voices, a participatory ICW project carried out by and for HIV positive women, researched services available for HIV positive drug/alcohol using women living in London, UK, and explored their experiences of using these services. The women reported that present-day services do not support their specific needs, and many expressed feelings of being invisible and discriminated against, even within the HIV community. The women also articulated their concerns about disclosing their HIV status and drug use to existing or new partners, family and friends, their children, colleagues and employers. Would existing partners leave them? Would their children

accept their diagnosis? Discussions and training regarding disclosure should be offered to women living with HIV. These can be facilitated by other HIV-positive women who can share their experiences of what worked and what did not. Specific peer support groups for HIV positive women who are drug users should also be encouraged as a way of supporting each other and exchanging information and experiences.

Available online at: www.siyanda.org/static/icw_vision_paper6.htm

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3. Sexual and reproductive health for HIV-positive women and adolescent girls: manual for trainers and programme managers

Produced by: Engender Health and the International Community of Women Living with HIV/AIDS (2006)

Sexual and reproductive rights apply to all individuals regardless of HIV status. Yet more often than not, the rights of HIV positive women and adolescent girls are not recognised or given priority. Health workers need both training and support to eliminate stigma and discrimination towards women living with HIV and to provide quality safe and compassionate care to HIV positive women. In general, there needs to be a greater awareness of the larger social context of issues such as those affecting sexuality, sexual health, access to care, and confidentiality. This manual is designed to provide information and structure for a four-day training and a two-day planning workshop that will enable programme managers and health workers in resource-constrained settings to offer comprehensive, non-judgemental, and quality care and support to HIV positive women and adolescent girls in the local context. The manual also urges male involvement and promotes a holistic approach to integrated SRH counselling and programme planning that links SRH and HIV/AIDS services. The curriculum consists of: an introduction for the trainers; detailed session guides; and appendices containing additional training materials and programming tools.

Available online at: www.siyanda.org/static/icw_manual_trainers.htm

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4. Meeting the sexual and reproductive health needs of people living with HIV

Produced by: Guttmacher Institute (2006)

As the prospects for people living with HIV have improved worldwide, AIDS activists and the global public health community have increased their focus on quality-of-life issues as well as length-of-life issues. Regardless of HIV status, the ability to express one's sexuality and the desire to experience parenthood are, for many, central to what it means to be human. Yet people living with HIV and AIDS - especially women - are often seen as irresponsible if they desire to have children, or face criticism for being sexually active. This paper argues that concerted actions on several fronts are needed: to ensure that women with HIV are not coerced or pressured into terminating a pregnancy, or into using certain contraceptive methods such as sterilisation; to expand contraceptive services; to offer psychosocial support for women contemplating childbearing; and to provide nondirective, nonjudgmental and confidential counselling to HIV-positive women, including those faced with unplanned pregnancies. Associations and networks of HIV positive people and community-based organisations run by and for people with HIV have a key role to play in realising these goals.

Available online at: www.siyanda.org/static/guttmacher_srhr.htm

5. Pregnant women living with HIV/AIDS: protecting human rights in programs to prevent mother-to-child transmission of HIV

Produced by: Centre for Reproductive Rights (2005)

This briefing paper from the Centre for Reproductive Rights examines how women's human rights need to be central to the development of Prevention of Mother to Child Transmission (PMTCT) programmes. These initiatives enable pregnant women living with HIV to significantly reduce the chances of their infant being born with HIV through giving the women access to medication that can prevent transmission during their pregnancy. The paper argues that if these initiatives are seen as primarily directed at the care of the infant and the prevention of HIV transmission, there is a danger that the human rights of the woman as the patient will be ignored. Governments must uphold the fundamental rights of women when implementing these programmes. This will guarantee the rights of the women, but it will also ensure greater effectiveness for the initiative.

The paper recommends a number of actions which governments should take to maintain the human rights of the women on these programmes. PMTCT programmes should follow strict guidelines regarding informed consent and confidentiality. Women should be fully informed and receive counselling prior to testing, and should also be fully informed before starting treatment. Healthcare providers need to be trained in human rights awareness, and given strict guidelines on consent, confidentiality and non-discrimination. Governments also need to tackle anti-HIV stigma in their societies and advance and protect the human rights of women in the home and the public sphere.

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC23935>

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6. A positive women's survival kit

Produced by: International Community of Women living with HIV/AIDS (ICW) (1999)

This briefing paper from the Centre for Reproductive Rights examines how women's human rights need to be central to the development of Prevention of Mother to Child Transmission (PMTCT) programmes. These initiatives enable pregnant women living with HIV to significantly reduce the chances of their infant being born with HIV through giving the women access to medication that can prevent transmission during their pregnancy. The paper argues that if these initiatives are seen as primarily directed at the care of the infant and the prevention of HIV transmission, there is a danger that the human rights of the woman as the patient will be ignored. Governments must uphold the fundamental rights of women when implementing these programmes. This will guarantee the rights of the women, but it will also ensure greater effectiveness for the initiative. The paper recommends a number of actions which governments should take to maintain the human rights of the women on these programmes. PMTCT programmes should follow strict guidelines regarding informed consent and confidentiality. Women should be fully informed and receive counselling prior to testing, and should also be fully informed before starting treatment. Healthcare providers need to be trained in human rights awareness, and given strict guidelines on consent, confidentiality and non-discrimination. Governments also need to tackle anti-HIV stigma in their societies and advance and protect the human rights of women in the home and the public sphere.

Available online at: http://www.siyanda.org/static/icw_survival_kit.htm

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Other recommended readings

1. Speaking freely, being strong

Author(s): L. Stackpole-Moore

Published by: Panos AIDS Programme (2006)

This report from Panos outlines the findings from research done on the role of communications in social mobilisation around HIV, in South Africa, Namibia and Brazil. Based on oral testimony from members of actions groups campaigning on HIV issues, it highlights the importance of communication at a personal, interpersonal and public policy level for such groups. The authors argue that small, informal community-based HIV groups have an important role to play in responding to the immediate needs and concerns of their members. Such groups enhance the visibility of people living with HIV and can provide a platform for challenging government and other policymakers. However, strong movements can also dominate the debate and create a polarisation between civil society and government. People living with HIV need additional communication skills to enable more accurate and ethical coverage of HIV in the media.

The report recommends greater support for capacity development among members of HIV social movements to facilitate greater communication. There is a need to develop better links between the members of these movements and the media, and to provide media professionals with better guidance on how to cover HIV issues. The report also recommends promoting a greater diversity of spaces for carrying on debates about HIV issues, and encouraging a more diverse range of voices to participate in these debates.

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC24113>

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2. Show us the money: is violence against women on the HIV/AIDS donor agenda?

Authors: Fried, S.

Published by: Women Won't Wait (2007)

This research report from the Women Won't Wait Campaign highlights the lack of priority given to tackling gender-based violence against women by the major international HIV funding organisations. The research found that the funding bodies continue to treat violence against women as a supplementary issue rather than as something integral to all aspects of their work on HIV. Funding for programmes which combat gender-based violence is a separate stream and these initiatives have not benefited from the increase in funding for HIV programmes in the last number of years. It is very difficult to track the exact amount of money the major funding bodies are devoting to these initiatives and difficult to hold them accountable on this issue.

The report recommends that these institutions develop a clear policy framework that gives priority to violence against women and girls, and the link with HIV. These bodies should begin to encourage collaboration between groups working on violence against women and those working on HIV, and develop links between the HIV and the sexual health and reproductive rights sectors. The report also recommends that the funding bodies should create a specific mechanism for measuring work that addresses violence against women in all HIV action plans, and should support research to increase the level of knowledge on the links between gender-based violence and HIV.

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC24243>

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3. Off the map: how HIV/AIDS programming is failing same-sex practising people in Africa

Authors: Johnson, C A

Published by: International Gay and Lesbian Human Rights Commission (IGLHRC) (2007)

This report from the International Gay and Lesbian Human Rights Commission (IGLHRC) explores the ways in which governments, international donors and NGO's (non- governmental organisations) are denying basic human rights protection to same-sex practicing Africans. It describes how HIV interventions are not being directed towards the needs of same-sex practicing people and the negative impact which this is having on the response to the HIV crisis in Africa.

The report uses a sexual rights framework to analyse the homophobia and denial about same-sex practices that are widespread in African culture and politics. Same-sex practicing people, and gender non-conforming people, experience significant discrimination and their human rights are not being protected by governments. Because of the widespread denial about same-sex practices few resources are devoted to the specific issues of same-sex HIV transmission, or to the particular needs of same-sex practicing people living with HIV. This situation is compounded by: the restrictive reproductive health policy of the United States, one of the largest donors to HIV; and by the mixed record of NGO's in responding to the needs of same-sex practicing people. The report makes a range of recommendations, including the removal of all laws which criminalise and discriminate against same-sex practicing people and the promotion of equality and human rights. It also recommends that governments, international donors and NGO's actively encourage local LGBT (Lesbian, Gay, Bisexual and Transgender) organisations and develop and support HIV interventions directed towards same-sex practicing people.

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC24025>

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4. Saving lives by reducing harm: HIV prevention and treatment for injecting drug users

Authors: Open Society Institute International Harm Reduction Development Programme

Published by: Open Society Institute (OSI) and Soros Foundations Network (2006)

This report from the International Harm Reduction Development Programme at the Open Society Institute argues that HIV infection is spreading rapidly among intravenous drug users (IDU) because of a lack of effective measures to reduce drug consumption. It finds that worldwide 10 per cent of HIV infections are due to injecting drug use, and this rises to 80 per cent in Eastern Europe and Central Asia. The paper argues that the most effective approach to controlling drug use is not punitive anti-drug policies but the provision of harm reduction programmes.

According to the report, harm reduction programmes help drug users who are unable or unwilling to abstain from drug use to make positive changes to protect their health and the health of others. The paper outlines a five point harm reduction strategy. This includes making opiate substitution and effective drug-free treatment widely available, and scaling-up the provision of syringe exchange programmes. The report recommends increasing the provision of anti-retroviral therapy (ART) to drug users who need it, and the development of sexual health programmes directed at the needs of drug users. The report also calls for the reform of drug laws to prevent widespread imprisonment of drug users and more measures to protect drug user's human rights.

Available online at: <http://www.eldis.org/cf/rdr/rdr.cfm?doc=DOC24235>

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<http://www.eldis.org/hivaids/index.htm>

See the complete list of new additions, announcements, job adverts at: www.eldis.org/hivaids

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- HIV and AIDS Resource Guide - <http://www.eldis.org/hivaids/index.htm>

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