Ensuring equitable access to antiretroviral treatment for women

WHO/UNAIDS Policy Statement

Introduction

WHO and UNAIDS are actively promoting the scale-up of programmes to deliver antiretroviral therapy (ART), with the aim of reaching three million people by the end of 2005 (‘3 by 5 Initiative’). Equity in access to HIV treatment is a critical element of the ‘3 by 5’ and will contribute to the broader ‘right to health’ for all. Attention must therefore be given to ensuring access to ART and other treatment, care and prevention, for people who risk exclusion including on the basis of their sex. Currently there is limited information available on the sex and age distribution of those receiving ART, however, we know that gender-based inequalities often affect women’s ability to access services. Attention is therefore required to ensure that women and girls have equitable access to ART as it becomes available.

Gender-based inequalities put women and girls at increased risk of acquiring HIV. Women’s limited ability to negotiate safer sex practices with their partners, including condom use, can place even women who are faithful to one partner at risk of HIV infection. Married adolescent girls may be particularly vulnerable. Sexual violence, including rape, likewise increases the risk of HIV for women and girls. In addition, they typically have less access to education, income-generating opportunities, property ownership and legal protection than men. This means many women are not able to leave relationships even when they know that they may be at risk of HIV.

Gender inequalities also affect women’s access to and interaction with health services, including those for HIV prevention and AIDS care. To address gender-based inequities in HIV treatment, care and prevention, it is crucial to consider the different needs and constraints of women and men when accessing HIV services in different settings – and design interventions accordingly. For example, women’s access is more likely to be affected by restricted mobility, difficulties in accessing transport and childcare and lack of treatment literacy, as compared to men’s. In addition, women have specific reproductive health concerns which need to be addressed by HIV treatment and care providers. As gender intersects with age, ethnicity, social and economic status and other social categories, these barriers can vary across settings and within populations, often creating different sets of issues for adolescent girls and boys, and for women and men in different situations (e.g. migrant workers, sex workers, housewives, others).

This policy brief identifies actions needed to address the gender dimensions of equity in access to ART. A more detailed programmatic guide to help HIV treatment programmes address gender issues is currently being developed by WHO.

To adequately address gender issues in the scale up of ART, action is required in four areas:

- Development of a supportive policy environment
- Strengthening health systems to make them more responsive to the specific needs of women and men
- Promotion of programmes that overcome obstacles to equitable access
- Development of benchmarks and indicators to measure progress

1 For more guidance on reaching equitable access for specific populations please refer to ‘Guidance on Ethics and Equitable Access to HIV Treatment and Care’ (WHO/UNAIDS, 2004).
The vulnerability of women and girls is well documented: in sub-Saharan Africa overall, women are 30% more likely to be infected with HIV than men and 15-24 year old women are approximately 3 times more likely to be infected with HIV than their male counterparts. As of the end of 2003, almost half (17 million) of the 35.7 million adults living with HIV globally are women. (UNAIDS, 2004: Report on the Global AIDS Epidemic)

1. Development of a supportive policy environment

Advocating for gender equality

The promotion of gender equality as part of fair distribution processes should be clearly articulated in policy statements and work plans.

In order to reduce gender inequalities in the context of HIV, advocacy needs to go beyond the health sector and promote social change more broadly, addressing root causes of gender inequality. For example, elimination of violence against women, equal protection for women under the law as well as equal access to education and property rights should be advocated. Even though achieving these changes is a long-term process, transformation in these areas is critical for creating an enabling social environment and thus, facilitating prevention and treatment access for women and girls.

Advocacy activities should target communities, policy makers, donors, programme managers, service providers and the media to help mobilise public support for programming that addresses the specific needs of women and men, boys and girls, in HIV prevention, treatment and care, including access to sexual and reproductive health information and services.

Ensuring equity within the health system

Advocacy efforts should also focus on reforming legislation and personnel policies within the health sector to ensure equal opportunities for women and to redress discrimination and inequities in the sector itself. For example, in many health care settings female health care providers face higher workloads, lower salaries, and fewer opportunities for promotions and decision-making. Addressing such inequities will contribute to increasing morale among service providers and lead to a safer and more supportive environment for all staff. This will in turn improve their capacity to support their clients.

Expanding eligibility criteria

It is important that eligibility criteria for priority access to ART include social in addition to medical criteria. Furthermore, criteria for need and eligibility for ART should not be discriminatory and must ensure fair access to ART for vulnerable and disadvantaged groups (e.g. rural women, sex workers, widows, young women).

Promoting the active participation of people living with HIV

The active participation of people living with HIV, including women and girls, is of paramount importance when designing effective strategies for HIV treatment and care. In order to promote equitable access to ART and care for women and girls, networks of women, especially of women living with HIV, need to be involved at all levels to adequately consider their perspectives in planning, implementation, monitoring and review of scale-up programmes.

2. Strengthening health systems to make them more responsive to the specific needs of women and men

Strengthening health systems to support the scaling up of ART is essential to increase coverage and to sustain the scale-up of ART, care and prevention. Specific needs and circumstances of women and men across age groups must be adequately addressed. These include:

Integrating HIV related services

In order to address the broad range of needs of people living with HIV and AIDS, ART needs to be provided as part of integrated HIV prevention,
treatment, care and support. Women will particularly benefit from such an approach as they have less time, mobility and resources to access separate services.

In addition, the integration of AIDS services with sexual and reproductive health services (e.g. family planning and antenatal care) can help address women’s different needs and reduce stigma.

Similarly, as men are more likely to use TB and STI services, integration of AIDS services may facilitate greater coverage and access to treatment for men and boys. The way services are integrated or linked should be determined at the country level based on the type of services, administrative structures and available resources as well as the profile of the epidemic.

Financing ART programmes

Women are chronically disadvantaged in their access to cash and productive resources. Insufficient funds or lack of control over household expenditures frequently prevent women from accessing ART. Thus cost-sharing schemes often disadvantage women more than men. Free provision of ARV drugs at the point of service may result in increased enrolment and sustained adherence rates for women and young people in particular.

Selection criteria regarding who will receive free therapy, who will receive subsidized ART and who will pay out of pocket fully should consider the impact of ART costs on access for women. The guidance principle should be fair distribution. As the cost of ART is a major barrier for women in particular, serious consideration must be given to abolishing user fees altogether as part of a strategy for protecting women’s access to HIV treatment and care.

Strengthening home and community based programmes

Home and community based care programmes involving community members, e.g. nurses, community health workers, volunteers, and family members, and HIV positive people (who may also be any of the above), are critical to the provision of good quality chronic care. Such programmes therefore, should be supported and integrated into national AIDS plans.

However, these programmes must recognise the gender dimensions of care giving, especially within families, and the opportunity costs to the primary care givers—most often women (particularly older women) and girls. Providing care can also exert great pressure on care givers, often leading to exhaustion, depression and a neglect of their own health and income (e.g. unattended crops, time off work). Case studies show that young girls often leave school to help their families by providing care or economic support. This can limit their development and place them at risk of exploitation.

Therefore, it is necessary to:

a) Find ways to support and sustain care givers, including providing nursing care information and materials, counselling and linking with local support services. Linkages should also be developed between health services and community based organizations working on HIV/AIDS issues, such as legal protection, assistance with property and inheritance rights, nutrition programmes and income generating schemes, as these linkages would also assist households financially and support women in providing care to family members.

b) Redistribute the burden of care in communities and actively involve men and boys.

c) Invest in informal education initiatives that can reach girls and boys out of schools.

Building capacity for health care workers and other care givers

Capacity building incorporating gender sensitization will be required to improve knowledge, attitudes and skills of health workers and care providers who will be in the frontline of ART programs. Training should address not only clinical issues, but also personal attitudes, biases and values of service providers towards those affected by AIDS or living with HIV - as use of services and treatment adherence are directly influenced by patients’ and communities’ trust in services and staff. In addition, health workers themselves may
be living with HIV and fear being tested because of stigma, and this also needs to be addressed.

Availability of treatment is likely to encourage more people, women and men, to seek HIV testing. However, concerns about stigma and violence (especially experienced by many women) may prevent them from seeking testing and counselling services. Similarly, in settings where medical procedures performed on women require their husband’s consent (including the need for permission to access health centres), a potential for conflict with confidentiality and informed consent arises. Health providers need training and support on disclosure, confidentiality, informed consent and other ethical issues related to ART scale-up.

This training should also include recognition of specific risks for women of HIV disclosure, such as partner violence, which may affect their ability to use HIV services and adhere to ART. The specific health sector response to violence against women will need to be decided in each context based on existing resources, referral options and services available.

3. Promotion of programmes that overcome obstacles to equitable access

Addressing gender-related barriers to access

Gender-related barriers are expressed in the geographical, financial, social and cultural accessibility of health services, including HIV services. Barriers to accessing health services in terms of cost, location, distance to the facility and clinic scheduling often affect men and women differently. For example, men may be unable to take time off work to approach services for testing and follow up. Women may have restricted mobility, be unable to arrange childcare and often have fewer means to cover any direct or indirect costs (such as transportation).

The design and implementation of ART programs must therefore address issues of transport and distance, opening hours and waiting time in clinics, as well as those of cost-recovery (e.g. criteria for whether, who and how much should people pay for services and medicines). For example, treatment programmes could explore the possibility of community-based delivery of ART in community centres or mobile clinics so that women do not have to travel long distances. Some key ways to improve the responsiveness of programmes to women’s and men’s needs may include:

a) Conducting a rapid assessment which provides information on which groups are particularly hard to reach, why this is so, where treatment is provided and whether it is accessible to all eligible patients. These assessments should address the impact of gender- and age-related barriers on access to services – including existing stigma and discrimination – as well as the effective delivery of information about all aspects of AIDS, including treatment options, to different groups of patients.

b) Supporting community-based organizations involved in care and ARV delivery to expand and decentralize services to reach women in rural areas and among marginalized populations.

c) Involving HIV positive women’s groups. They can give very valuable feedback on ways to reach women living with HIV who have difficulty accessing services, can support women in counselling, treatment preparation and adherence, and can help empower women and girls to access services that provide ART, care and HIV prevention services.

Reaching marginalised groups

When designing programmes for vulnerable or marginalised populations such as young people, migrant workers, sex workers, drug users and refugees, it is important to ensure that data are disaggregated by sex and age and that an assessment of the differing needs of men and women within these populations is also conducted. At the same time, health programmers must carefully balance more focused programming for marginalized groups with programming for the wider population to avoid stigmatizing them as ‘AIDS carriers’ or ‘AIDS vectors’.
Ensuring that women and men have access to reliable AIDS information

Providing sound information about the availability and benefits of ARV treatment will stimulate demand for treatment and help sustain treatment adherence. As literacy among women is particularly low in many settings, non-written means of communication, such as pictograms, radio, drama and songs can better convey AIDS messages. Information that is culturally and linguistically appropriate must be disseminated widely. In addition, specific messages should be tailored to reach and address the concerns of women and men, and those of male and female adolescents.

Addressing gender issues in HIV testing and counselling

HIV testing and counselling services are an essential part of ART programmes. Men and women experience different barriers to HIV testing and different consequences of disclosure, reflecting gender norms in their community. For example, some studies show that women are often not told of their status first - their husbands or in-laws may be told first. Women are also blamed for bringing HIV into the family and are at risk of abuse and ostracism. Men might be unwilling to have an HIV test for fear that they may lose their jobs or be ostracised at work.

Perception of risk by married women:

The decision to seek testing is influenced by risk perception. Married women who are faithful to one partner may not perceive themselves to be at risk. Prevention messages need to encourage knowledge of HIV serostatus, and help men and women assess their specific risks in addition to providing general information about HIV.

Considering possible consequences of HIV testing and disclosure:

Reasons commonly given for avoiding HIV testing are lack of perceived need and fear of negative outcomes from disclosing one's HIV status, including fear of stigma, discrimination and violence. Stigma and negative outcomes of disclosure appear to be more common when a woman is tested prior to her partner, and when the woman is the HIV-positive partner in serodiscordant couples. Strategies to minimize negative consequences of testing for women include: couple counselling and testing, mediated disclosure by a trained counsellor and education of communities and family members (men, older women) to reduce discrimination of women and girls who test positive. Women who want to disclose to their partner or family may require separate counselling and support strategies.

Creating multiple entry points for ART

Although antenatal care is an obvious entry point for women in need of ART, the focus of these services has until recently been limited to preventing transmission from mothers to children, with limited benefits to mothers with HIV.

WHO/UNAIDS advocates a comprehensive four-pronged approach to prevention of mother to child transmission (PMTCT): primary prevention of HIV infection among women, prevention of unwanted pregnancy among women with HIV, prevention of HIV transmission during pregnancy, childbirth and infant feeding and sustained long-term care and support (including ART) for women with HIV and their families. Coverage of such PMTCT programmes must rapidly increase coverage.

Entry points for non-pregnant women and girls to HIV testing and counselling and to ART need to be readily accessible. ART needs to be made available through a much wider range of health services to ensure access wherever different groups are in contact with the health system. For example, this can be done by linking ART programmes with primary health care, family planning, tuberculosis and sexually transmitted infection services or health services at the workplace.

Providing gender sensitive adherence support

Fear, stigma and misinformation also affect adherence to ART. For example, the misconception that drugs can harm the fetus has been reported among pregnant women in some settings. Similar factors that prevent women from seeking health services such as lack of time, lack of child care, lack of privacy, workload, and fear of unintended
disclosure of HIV status may also interfere with ART adherence. Programmes should therefore include strategies for treatment support and follow up that are acceptable to men and women in need of ART.

Offering reproductive health services for women and girls on ART
Women with HIV/AIDS will need to be counselled appropriately about their options and choices for contraception, pregnancy and childbirth. Women may also require treatment for sexual and reproductive tract infections.

4. Development of benchmarks and indicators to measure progress
Fair distribution and gender equity when ART resources are scarce will only be achievable if benchmarks are set and indicators are in place to measure and analyse sex- and age-specific trends, achievements and failures of ART programmes.

Setting targets for women and men
Countries should be advised to define specific targets for women and men to be reached through ART programs based on their local epidemiology.

Monitoring and evaluation
As ART programmes are implemented, monitoring should be ongoing in order to identify who is being reached and who is not, and to make necessary adjustments in guidelines, program designs and implementation strategies, including staff training and supervision. Sex and age disaggregated data must be collected and reported concerning the numbers of people attending testing and counselling services, as well as the number of people living with HIV referred to ART services and receiving ART and home care. Non-adherence, drop out rates, morbidity and mortality must be monitored for differences between women and men which can be specifically addressed. In addition, data on geographical (e.g. urban/rural) and socioeconomic distribution should be collected where possible.

All data should be assessed to see whether the goals and targets set in the policies are being met, with necessary adjustments in strategies made to achieve equitable access.

Examining the impact of ART financing on women
As countries roll out ART programs and consider their options for financing care and treatment, they must take into account how drug costs, user fees or cost-recovery mechanisms might adversely affect women.

Commissioning new research
At present, operational research on gender equity in access to ART is nascent. In addition to collecting sex and age disaggregated data on who is currently accessing treatment services and conducting 'situation assessments', it is also necessary to research women’s and men’s perspectives on the design and delivery of HIV treatment, care and prevention. More research is also needed on factors that impede men’s access to testing and counselling as well as to treatment services.

There is also still insufficient research on the response of the health sector to adolescents with HIV, and on differences in the barriers that young women and men face in accessing AIDS treatment, care and support. More attention should be focused on increasing participation of women in clinical research and in drug and vaccine trials.

Sharing promising practices
Treatment interventions that integrate equity concerns must be documented and shared as 'good practices'. For example, the experiences of women participating in PMTCT and ART programs can provide valuable input to the design and scale-up of other AIDS programs and inform the development of successful strategies for promoting equity in other areas of public health.

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