

**GENDER MATTERS: OVERCOMING  
GENDER-RELATED BARRIERS TO PREVENT  
NEW HIV INFECTIONS AMONG CHILDREN  
AND KEEP THEIR MOTHERS ALIVE**



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## **GENDER MATTERS: OVERCOMING GENDER-RELATED BARRIERS TO PREVENT NEW HIV INFECTIONS AMONG CHILDREN AND KEEP THEIR MOTHERS ALIVE**

### The evidence

Approximately 660 children globally are estimated to acquire HIV every day, mostly during pregnancy, birth or breastfeeding (1). If pregnant women living with HIV and their children both have timely and continued access to antiretroviral medicines, it is possible to reduce new HIV infections among children to less than 5% (2). Furthermore, enrolment in services to prevent new HIV infections among children is increasingly being seen as an opportunity to enable women to access HIV treatment and care for their own health and well-being (3).

While effective approaches are available to prevent new HIV infections among children and keep their mothers alive and healthy, in countries with a high HIV burden, access and adherence to these services remain weak, even when they are available. In 2013, 33% of pregnant women living with HIV globally did not receive antiretroviral medicines to prevent new HIV infections among children (4), and rates of non-adherence also have been found to be high—up to 40% in one study (5)—among those who do access services. Among pregnant women receiving antiretroviral medicines to prevent vertical transmission in 2013, 49% were receiving lifelong antiretroviral therapy. (6).

Reports by women living with HIV strongly indicate that gender inequality related to cultural and economic issues can pose a major barriers to women's access and adherence to HIV treatment services (7). Alerted by these reports, the Secretariat of the Joint United Nations Programme on HIV/AIDS (UNAIDS) undertook qualitative rapid assessments of gender-related and cultural barriers to access HIV services (8). The assessments were undertaken in partnership with women living with HIV at six sites in five high-burden countries: the Democratic Republic of the Congo, Ethiopia, India, Nigeria and Uganda. These countries are among the countries with the highest burden of unmet needs for preventing new HIV infections among children, collectively accounting for 48% of the gap in provision of services to prevent new HIV infections among children globally (1).

### The barriers

Studies indicate that harmful gender norms and practices, cultural perceptions and beliefs surrounding pregnancy and childbirth, and a distrust of health-care services all can pose barriers to HIV prevention and treatment (10). In particular, women face difficulties related to unequal gender power relations and stigma (11).

Lack of women's autonomy over their sexual and reproductive health has been found to be associated with reduced uptake of maternal health services (12). For example, a 2006 survey indicated that the majority of women in India who did not attend antenatal care were prevented from doing so by their husbands or family; by comparison, the proportion of women who did not attend based on their own decision was very low (13).

Mistrust of health services, particularly due to a lack of cultural sensitivity and confidentiality among health-service providers, has been linked to non-utilization of services by women (14).

In Liberia, a 2011 study identified the cultural practice of confining dialogue surrounding pregnancy to women and discouraging discussions about childbirth. The participants of the study related this normative cultural discretion to the perceived dangers of sharing information about birth and pregnancy, which ultimately influenced the type of care that they sought. Women in the study distrusted the formal health-care system and preferred to deliver at home with traditional birth attendants who understood community norms and practices (15).

Stigma against women living with HIV is both widespread and severe (17). Studies have found that women are deterred from accessing services by fear of abuse and mistreatment related to the stigma of being identified as living with HIV. (18) A 2011 study conducted in Ethiopia documented how women frequently refused to enroll in programmes to prevent new HIV infections among children and discontinued antiretroviral therapy for fear of revealing their HIV status to their husbands, an action that could have negative consequences for their marriage (including divorce) (14). These fears are related to unequal economic opportunities for women, which make it difficult for a single mother to support herself and her children. A 2007 study in Malawi, undertaken during the roll-out phase of the national programme to prevent new HIV infections among children, found that four in ten women who were living with HIV and utilizing services to prevent new HIV infections among children had been divorced by their husbands because of their HIV status (19). Since the 2011 introduction of Option B+ in Malawi, offering lifelong treatment to all women living with HIV regardless of immunological stage, 27% of women are lost to follow-up after 12 months, indicating various factors still persisting that inhibit them from accessing care and services (20).

Conversely, approaches that empower women and engage male partners in antenatal care appear to contribute to women's utilization of services to prevent new HIV infections among children and keep mothers alive. In a 2013 review, the World Health Organization (WHO) found that working with men and boys to promote gender equitable attitudes and behaviours is a promising programme approach to addressing violence against women in the context of HIV (21). Support from peers and extended family also appears to support women to access HIV and antenatal services (21).

Guided by a brief review of previous studies, the rapid assessments revealed key gender-related barriers to preventing new HIV infections among children and keeping their mothers alive. These included stigma against women living with HIV; gender power relations; fear of violence and abandonment; traditional and cultural gender roles concerning pregnancy and childbirth; and community perceptions of health services and health-service providers. Although the identified barriers are context specific, raising awareness about life challenges faced every day by women living with HIV and encouraging countries to meaningfully engage women living with HIV in service design and implementation will contribute to addressing gender-related barriers more widely. This, in turn, will help eliminate new infections in children and keep their mothers alive and healthy.

## Stigma against women living with HIV

Some participants in the rapid assessments expressed a cultural belief that women were primarily responsible for spreading HIV. Such a perception, combined with a deeply rooted fear of witchcraft, leads some to blame women who test HIV-positive for bringing it into the families, even if their partners have tested HIV-positive first. Thus, HIV was found to be associated with perceptions about women engaging with multiple partners, further stigmatizing them, particularly given the taboos and social control related to female sexuality. These beliefs correspond with the findings of the People Living with HIV Stigma Index, which has documented the frequency and severity of reported stigma and discrimination against women living with HIV.

Many participants in the rapid assessment indicated that women living with HIV were considered to be immoral. As a result, they face more negative attitudes than men. In the words of a woman living with HIV:

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*For a man, the community says, “let it be, because he is a man”; if it is a woman, they say, “she is a woman, how come [she got the disease]? She must have caught it fooling around.”*  
(Woman living with HIV in Ethiopia)

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At all rapid assessment sites, participants held the view that women living with HIV should not get pregnant, believing that the mothers would soon die and the babies would be born with HIV. They felt it was irresponsible for women living with HIV to become pregnant because they were considered to be less capable of tending to their children’s needs.

This key finding had a significant impact on pregnant women. Not only did it discourage them from being tested for HIV or following up with antiretroviral drugs, but the stigma was internalized by some pregnant women living with HIV. These women reported going through periods of depression upon learning of their HIV-positive status, and they did not seek treatment because they believed that there was no hope for them. Some pregnant women living with HIV also felt guilty, believing that they had exposed their children to HIV. In the words of a woman living with HIV:

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*My morale went low until it got to zero. I tried to commit suicide many times. One day, I wanted to take poisoned water. Should not my firstborn daughter be there, I would have killed myself already.*  
(Woman living with HIV in the Democratic Republic of the Congo)

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Fear and actual occurrences of discrimination by health-care workers were reported as a major deterrent to pregnant women being tested for HIV, taking medication to prevent HIV transmission to their child. According to some participants, simply being seen at health facilities where HIV treatment is provided would lead people to assume that a person has HIV,

resulting in gossip. To avoid having their status revealed, people living with HIV travelled far to access treatment; some women even avoided antenatal clinics where HIV testing was carried out, preferring ignorance to possible stigma and the related stress.

Some participants noted that a perceived (and sometimes actual) lack of confidentiality from health-care workers, along with the stigma and discrimination in their community that would result if their status became known, deterred women living with HIV from accessing services to prevent new HIV infections in children or from continuing the treatment. In the words of a woman living with HIV:

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*When I was pregnant with my second child, I started a follow-up at a private clinic. When the nurse knew and informed me [of] my HIV-positive status, she advised me, “You don’t need to give birth with this situation, never. You are [HIV-]positive, and you need to terminate the pregnancy.” But my husband and I said, “God always has His ways,” and we decided to have the baby ... We delivered a healthy baby whom after some years we took and showed to the nurse.*

(Woman living with HIV in Ethiopia)

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## Gender power relations; fear of violence, and abandonment

Unequal gender relations and women’s socioeconomic dependency were found to limit their decision-making power regarding accessing HIV and maternal health services. Male partners or other family members sometimes refused to allow pregnant women to visit antenatal clinics because they did not trust the efficacy of the services, did not want to pay a fee (either for transport or the actual services), or (in the case of husbands and partners) feared the stigma that might be directed at them if their own HIV-positive status was somehow discovered through the woman’s treatment. Women feared abandonment because of the lack of economic opportunities for a woman to support herself and her children should her husband leave her (or her family abandon her) due to her HIV-positive status. Fear of being blamed for HIV—and thus being physically or emotionally abused or abandoned—sometimes led pregnant women to avoid disclosing their status and accessing treatment services. In the words of a woman living with HIV:

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*The reason I refused to disclose to him is that the man had earlier on threatened that if he finds out that I am [HIV-] positive ... he would kill me.*

(Woman living with HIV in Nigeria)

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Women tend to access antenatal services at different stages of their pregnancy. For example, many women only go to an antenatal care clinic when they already are in labour. While some health workers attribute the delay in seeking antenatal care to poverty, domestic chores, and distance to the health facility, some women indicated that their access to services was limited by a lack of autonomy. In the words of a woman from the community:

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*My in-laws decide about [going to a health-care facility]... If I step out of home without permission, I will be scolded at home. People in the village will raise a finger at me, saying “what kind of a woman is she who does everything on her own?”*

(Pregnant woman in India, HIV status unknown)

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## Traditional and cultural gender roles concerning pregnancy and childbirth

Traditional customs or beliefs related to conception, pregnancy and childbirth sometimes act as barriers to accessing services that prevent new HIV infections among children and keep mothers alive. The message shared by most participants in the assessments is that pregnancy and delivery are women’s issues; as a result, there were times that women did not seek care from family or others, as they felt they should bear it on their own. At the same time, beliefs that childbirth is a normal occurrence that does not require medical care also were factors in the low utilization of antenatal care services, which then affected access to HIV services.

Male involvement in women’s visits to antenatal clinics and in services to prevent new HIV infections among children and to keep women alive and healthy was generally limited. The lack of male involvement was sometimes a barrier to testing and accessing treatment, as pregnant women living with HIV needed help with transportation to clinics and receiving (and taking) antiretroviral drugs; they also required emotional support, particularly in the face of stigma from family members or the community at large. Men reported that their lack of involvement was due to fear of social embarrassment, stigma and exclusion at health clinics, or that it was simply the result of disinterest in what was considered a “woman’s affair.”

Women’s fear of revealing their status because they were not breastfeeding also was mentioned as a barrier. In the words of a community member:

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*After delivery, if [the mother] doesn’t breastfeed, then she is asked, “Why aren’t you breastfeeding? What’s your problem?” [Mothers] of course don’t openly say what their problem is ... then it’s very difficult for them to answer these questions. Also, the first 40 days or a month, the woman has to live with her mother-in-law or sister-in-law, then it becomes problematic. [They ask], “why are you taking so much care?”*

(Counsellor in rural India)

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## Community perceptions of health services and health-service providers

A wide range of gender-related barriers were identified by assessments participants with regards to local community perceptions of the effectiveness and safety of health services and the trustworthiness of service providers. These included perceptions of antenatal clinics and HIV testing, perceptions of HIV treatment, awareness and perception of services to prevent new HIV infections among children, and the availability and accessibility of comprehensive health services.

A belief in traditional health-care methods and treatments, as well as a lack of trust in modern medical interventions, can discourage both visits to antenatal care facilities and the use of HIV prevention and treatment services. Women in rural sites in the Democratic Republic of the Congo, India, Nigeria and Uganda frequently turned to traditional birth attendants over official health providers because they were considered more familiar, friendlier and more culturally aware. For example, in accordance with some Ugandan tradition, birth attendants bury the placenta cord facing upwards to retain fertility, while hospital attendants dispose of the placenta, an act that is believed to cause female infertility. Birth attendants also are considered less of a financial burden. In Uganda, for example, payment of a traditional birth attendant could be 3000 shillings (just over US\$ 1) or small material items.

Some differences were noted from site-to-site regarding attitudes about HIV treatment. Participants in the Democratic Republic of the Congo and Nigeria expressed ambivalence about antiretroviral medications, based on the fact that the therapy does not cure the disease. Several participants in the Democratic Republic of the Congo expressed the belief that antiretroviral medicines were considered to be types of sedatives or vitamins that make people feel good but have no impact on the progression of the disease (8). At the Nigerian site, several participants were of the opinion that antiretroviral treatment was dangerous, as it made people living with HIV look healthier, which meant that others could no longer identify them as having HIV. Such perceptions suggest that antiretroviral treatment—and the possibility for healthy living that it offers—is not fully understood, and it points to the pervasive stigma and discrimination that persists against both people living with HIV and HIV treatment. In the words of a community leader:

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*The government should stop giving drugs to those who are HIV-positive, as they come back healthy to infect others. Let them die.*

(Male community leader in Nigeria)

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Some people living with HIV reported combining antiretroviral therapy with traditional medicine and treatments. Others were concerned by the side effects of the antiretrovirals and discontinued the treatment. Still others living with HIV did not begin or continue antiretroviral treatment due to their cultural or religious beliefs, instead believing that they could be cured through their faith or that the disease is God's will or punishment.

Some participants at the Uganda site, however, showed determination to access their medication and daily dose of antiretroviral treatment after noticing the positive effect that treatment had on

their health. This suggests that once the importance of treatment is understood, its uptake may increase. As a pregnant participant living with HIV explained while visiting a Ugandan hospital to receive her antiretroviral treatment:

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*Antiretroviral therapy has helped to keep me alive and educate my children. I also hope that my child on antiretroviral therapy will be healthy and grow and play with his friends.*

(Pregnant woman living with HIV in Uganda)

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At all sites, most people living with HIV (and some women who had visited antenatal clinics) had heard of services to prevent new HIV infections among children. While some participants indicated that they had never heard of the services or were unaware that HIV could be transmitted from mother to child, others expressed disbelief that prevention of new HIV infections among children was possible. Even women who had successfully used the services and given birth to children without HIV indicated that they had previously held these beliefs. In the words of a woman living with HIV:

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*The community finds it hard to believe that an HIV-positive mother would deliver [an HIV-] negative child. Even I found it difficult to believe, except for the fact that I have [an HIV-] negative child. That is what made me believe.*

(Woman living with HIV in Nigeria)

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In terms of the availability and accessibility of comprehensive health services, participants highlighted resource problems as barriers to health services, particularly for preventing new HIV infections among children. These resource problems ranged from a lack of service availability in certain areas—which lead to more difficult travel and increased expense for people living with HIV—to undersized, underequipped and understaffed health facilities. For example, many health facilities offered antenatal care, but not HIV testing and services to prevent new HIV infections among children and keep mothers alive (or vice versa). Similarly, some women were referred to clinics that were inconvenient for them to attend, while other women, knowing the difficulty of accessing services, did not bother to get tested at all. These barriers often coexist with each other: the remoteness of a village, for instance, combined with poor roads, expensive transportation and inadequate human resources can have negative consequences on health-system coverage. Lack of resources also can lead to patients being shuffled from one health centre to another, a problem that is exacerbated if transportation is lacking or inadequate. In the words of a woman living with HIV:

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*What is the use of testing when you know you cannot access medicine from your nearest health centre, and you can't travel to reach where the medicine is given? This can worsen your health with stress and probably kill you, so it is better when you don't confirm your HIV status.*

(Pregnant woman living with HIV in Uganda)

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The correlation between the quality of the services provided and out-of-pocket payment came up frequently, but even when services were free, the costs (and opportunity costs) associated with taking time to access services to prevent new HIV infections among children and protect the health of women were cited as a barrier. Many women reported that they lacked the time to visit health centres, or that they had no one to take care of their responsibilities in their absence. Health-care workers at all sites reiterated the opinion of community members that the quality of services was severely affected by a lack of resources, including a shortage of well-trained staff.

## The way forward

After more than 30 years of the HIV epidemic—and an unprecedented medical and social response—discrimination, violence, harmful gender norms and related stigma continue to pose challenges to an effective HIV response. The findings of these assessments indicate that gender-related barriers pose significant obstacles to the uptake of services that prevent new HIV infections among children and keep mothers alive—obstacles that require urgent attention. Without dedicated attempts to overcome these gender-related barriers, current efforts will meet with limited success, and the needs and rights of both women and children will remain compromised.

Overcoming these barriers requires targeted and sustained investment, but there are significant potential returns on that investment—by addressing these obstacles, it is possible to end new HIV infections among children and to protect the rights and health of women living with HIV. Based on the findings of these assessments and the outcome of discussions held in the selected sites in the Democratic Republic of the Congo, Ethiopia, India, Nigeria and Uganda, the following recommendations are proposed to overcome gender-related and cultural barriers to services. They are closely aligned with best-practice guidelines of agencies within the UN system, particularly the World Health Organization's *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection* (published in 2013), and they are intended to support the scaling up of comprehensive services as part of the continued implementation of the *Global Plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive* at the community and country level.

### 1. *Address stigma and discrimination against women living with HIV to increase utilization of and adherence to services.*

Given the frequency and severity of reported stigma and discrimination against women living with HIV (and its consequences in terms of accessing and adhering to services), addressing stigma and discrimination remains a key strategy for increasing the utilization of and adherence to HIV services. In order to address stigma and discrimination against women living with HIV, it is necessary to continue building awareness and sensitivity in communities, including through the use of local media and local language(s). Women living with HIV also must be supported to claim their human rights, including sexual and reproductive health rights. Engaging community leaders at all levels, including religious leaders, is an entry-point for beginning an informed dialogue on HIV-related stigma and discrimination.

## ***2. Address violence against women as part of programmes to prevent new HIV infections among children and keep mothers alive and healthy.***

Violence against women has been shown to be both a cause and a consequence of HIV, and as the findings of these rapid assessments reveal, it can significantly hinder women's access and adherence to services and treatment. Health services can be used as an entry point to identify and counter violence, provided that they deal in a non-judgmental manner with the complexities around violence against women and the underlying gender inequalities. They also can secure confidentiality for women living with HIV and promote respect for their rights.

Referral to appropriate medical and/or legal counselling and social services should be provided to survivors of violence. As the WHO programming tool notes, it is advisable to integrate violence services in all health-care settings. This includes HIV testing and counselling, prevention of mother-to-child transmission, and treatment and care services that mitigate the consequences of violence faced by women and avoid exposing them (particularly women living with HIV) to further violence.

## ***3. Support transformation of traditional gender roles related to maternal health, providing correct information on HIV by using culturally-appropriate, gender-sensitive and rights-based approaches.***

Transforming harmful gender norms is equally important to increasing utilization of and adherence to HIV services. Doing this requires engagement of the community in general—and of men and boys in particular—to challenge prevailing gender norms. It also must leverage the experiences and expertise of women living with HIV.

Building awareness and increasing sensitivity about reducing stigma, discrimination and violence among the extended families of women—as well as promoting uptake of services—is likely to contribute to transforming norms. Health services need to be delivered in a manner that is sensitive to culture and gender, while still upholding the rights of women and welcoming supportive male participation. More specifically, opportunities need to be created for voluntary attendance, counselling and testing for couples.

In order to be effective, information on HIV that is provided to communities in an attempt to overcome the barriers posed by misconceptions about HIV must be sensitive to culture and gender. It also must be comprehensive and rights-based.

## ***4. Address lack of awareness and mistrust of existing services to prevent new HIV infections among children and keep mothers alive and healthy.***

The identified lack of awareness and mistrust of modern medical interventions that can provide life-saving treatment are significant barriers to accessing services to prevent new HIV infections among children and keep mothers alive and healthy. Service provision must be rights-based, non-judgmental and confidential, and health-care providers must be sensitized to the link between cultural practices, gender inequality and the rights of women. Dissemination of evidence-based information about services and treatment must go beyond the contact between individual clients and health-care providers, instead reaching out to

communities as part of decentralized approaches and awareness campaigns. For consistency in messaging and the effective use of expertise, both women living with HIV and traditional birth attendants must be engaged in community mobilization efforts.

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