

“My husband and I decided that this baby should be born. But every time I go to my gynaecologist I feel like I mount the scaffold. She talks to me like I am a criminal.”

Snezhana, 32-year-old HIV-positive woman, Moldova

EXECUTIVE SUMMARY

VERTICAL TRANSMISSION OF HIV (commonly known as mother-to-child transmission)¹ has been virtually eliminated in the global North. This development – one of the rare, undeniable and ongoing success stories in the global response to HIV/AIDS over the past quarter-century – is due to most wealthier nations’ ability and will to provide HIV-positive women with testing, counselling, comprehensive prevention and treatment, including the best drug therapies available.

The situation is far different for women and families in poorer parts of the world, however. The vast majority of the 1.5 million women with HIV who become pregnant each year in the developing world do not have access to all (or, often, any) of these vital services. Only about one-third of them receive even the least effective drug regimen: a single dose of the drug nevirapine for themselves and another for their newborns, a therapy that has been shown to be at best, just over 40 percent effective in preventing vertical transmission. Most have no access to or knowledge of infant feeding guidance or support programs designed to keep mothers and infants alive and healthy, if in fact such programs actually exist in their countries or local communities.

The results are both tragic and outrageous: There are over 900 new cases of HIV in babies in developing countries every day but these should have been prevented because we know how (as evidenced in the developed world) it can be done.

MISSING THE TARGET – WOMEN IN THE SOUTH

Research conducted for *Missing the Target 7* by civil society activists on-the-ground in six countries (Argentina, Cambodia, Moldova, Morocco, Uganda, and Zimbabwe) shows that efforts to prevent vertical transmission are failing to reach the very group it was designed for – HIV-positive pregnant women.

One of the key reasons for this failure is that the emphasis of many country programmes has been narrowly focussed on providing antiretroviral prophylaxis to prevent the transmission of HIV to newborns and not on the other essentials - prevention, counselling, care and treatment services for women and children. Women’s right to sexual and reproductive health in particular is ignored.

¹ Along with a handful of governments and others, we have chosen deliberately to use “prevention of vertical transmission” in this report rather than the more common “prevention of mother-to-child transmission” or “PMTCT”, used by all the UN agencies and most governments. Activists around the world are campaigning to change the use of “PMTCT” as it adds to the stigma a woman faces by placing the blame on her for HIV transmission to her child. Some governments also call the program “PPTCT” or “prevention of parent-to-child transmission” to encourage greater male involvement. Many have also advocated for the use of “PMTCT Plus”, in an effort to move the focus from a child-only program to women and their families.

At an implementation level there is a shocking lack of consistency and coordination among the donors, UN agencies and governments. Poor coordination has resulted most notably in a lack of clear and accurate guidance being provided on infant feeding options to HIV-positive mothers.

In country after country, researchers were told of the widespread stigma and discrimination that HIV-positive pregnant women face, particularly in health care settings. As one research team noted, “Women alone bear the weight of preventing vertical transmission and the result of a possible positive HIV test.”

MISSING THE TARGET – THE GLOBAL PROMISE

In 2001, world leaders agreed to a goal of reducing the proportion of infants infected with HIV by 20 percent by 2005, and by 50 percent by 2010, including through ensuring that 80 percent of pregnant women accessing antenatal care have information, counseling and other HIV prevention services available to them.

*Declaration of Commitment,
UNGASS 2001*

Governments and UN agencies have failed to meet their international commitments and should be called to account. Despite the relative ease of delivering the antiretroviral prophylaxis to prevent vertical transmission progress has been slow, with global coverage rising from 9 percent in 2004 to 33 percent coverage in 2007. At least three quarters of HIV-positive pregnant women in 61 countries, including Cameroon, Ethiopia, India and Nigeria, are still not receiving this intervention.

Moreover, it is not enough merely to ensure access to ARV prophylaxis. Quality is equally important, and in this regard too the options for women in poorer countries are far less appropriate and effective. In the developed world, all women who want and need ARV prophylaxis can obtain triple-dose combination therapy, which reduces the risk of vertical transmission to a mere 2 percent. About half of women receiving ARV prophylaxis in the global South, meanwhile, are provided with single-dose nevirapine treatment. This regimen reduces transmission risk by just over 40 percent, however, and puts women under the risk of developing resistance to nevirapine, which is the backbone of many HIV treatment regimens in general.

But this is just one measure of the failure of efforts to prevent vertical transmission. Following the global commitment at UNGASS in 2001, UN agencies designed a comprehensive program to prevent vertical transmission. This program was based on promoting a woman’s right to a continuum of care starting with sexual and reproductive health and treatment through to psychosocial and nutritional support.

The four-prong strategy is stirring in focus and words, but actual progress and achievements have been far more limited. With the proportion of women among people living with HIV increasing in many regions, the world is failing to deliver prevention programs designed specifically for the benefit of women and girls.

We are failing to reduce the millions of unintended pregnancies in HIV-positive women every year. We are failing to improve women’s

In 2003, the UN adopted a comprehensive approach to the prevention of HIV infection in infants and young children based on a four-prong strategy:

1. primary prevention of HIV infection among women of childbearing age
2. preventing unintended pregnancies among women living with HIV
3. preventing HIV transmission from a woman living with HIV to her infant
4. providing appropriate treatment, care and support to mothers living with HIV and their children and families.

Guidance on Global Scale-Up Of The Prevention of Mother-To-Child Transmission of HIV, WHO 2007

access to HIV testing and counselling – in 2007, only 18 percent of the world's pregnant women were offered HIV tests. We are failing to stop the widespread discrimination against HIV-positive pregnant women by health care workers. We are failing to provide equal access to the most effective antiretroviral treatment for women no matter which part of the world they happen to live in. We are failing to ensure that every woman is supported to make informed decisions on the safest way of feeding her baby. We are failing to treat women and children – in 2007, only 12 percent of pregnant women living with HIV identified during antenatal care were assessed for their eligibility to receive ARV treatment.

Our research for this report, *Missing the Target 7*, has reinforced the need for governments, UN agencies, donors and indeed civil society to look beyond the magic bullet of administering a pill each to mother and baby in order to stem the annual toll of preventable infections and deaths in newborns.

OVERARCHING FINDINGS

For this seventh edition of *Missing the Target* researchers identified important barriers standing in the way of the continuum of services needed to successfully prevent vertical transmission:

- *The emphasis of governments and UN agencies has been on providing antiretroviral prophylaxis to prevent the transmission of HIV to newborns and not on the other essential prevention and treatment services for women and girls.* In many cases, neglect of the other services meant our researchers were not even able gather reliable data on provision of these services.
- *There is a significant and dangerous inconsistency between national policies and actual practice and the UN's global infant feeding guidelines.* Many researchers found a bias towards formula feeding and a lack of adequate support from health workers for women choosing to breast-feed. This results in unsafe feeding practices that increase the danger of post-birth HIV infection and/or of increased mortality and morbidity from diarrhoea and infectious diseases.
- *Country reports detail numerous ways in which health services are not designed or delivered to meet the needs of women:*
 - health services are hard to access or too expensive, particularly in rural areas
 - care is not accompanied by necessary support for adherence, travel and nutrition
 - services do not reach the many women who do not access medical facilities for delivery of their child or do so late in their term
- *Inadequate integration between vertical transmission programs, antiretroviral/HIV treatment services, maternal and child health, sexual and reproductive health services complicates access to services.*

- *Stigma, discrimination, violence* and the threat of violence are powerful realities in the lives of many women in the countries. This report's research chronicles numerous kinds of discrimination against HIV-positive pregnant women by health care workers, including breach of their right to confidentiality. This remains a key barrier in the uptake of services by HIV-positive women.

COUNTRY-SPECIFIC FINDINGS

The country case studies make clear that international partners share some of the blame, particularly because they too often fail to coordinate programs to help promote more integrated, comprehensive health care for women. However, it is equally clear that many of the obstacles are wholly local in nature: National governments and policymakers are often unable or unwilling to initiate or sustain health care programs and reforms that would improve women's access to services and, by extension, reduce rates of vertical transmission.

Four out of the six countries in the report are low-burden ones: Argentina, Cambodia, Moldova and Morocco. In these places, therefore, eradicating vertical transmission is within the countries' reach and could be accomplished in 1-2 years, given adequate resources and attention. In Uganda, where the epidemic is larger, this quest will take more time and will require more government commitment. In Zimbabwe, it is hard to see how progress will be made in the current context of absolute economic and political collapse. The fate of women and their children in that nation is likely to be improved only with the establishment of a new government that considers itself accountable to its citizens.

In addition to these overarching themes, there were unique findings in each country:

- In **Argentina** many pregnant women do not visit health centres until late in their pregnancy. There is no gender-specific HIV strategy within the government's HIV prevention program, and most cases of HIV infection among infants stem from the lack of antenatal care and insufficient information and counselling provided to women on HIV/AIDS and sexual and reproductive rights. Health care access varies widely across the country, and stigma and discrimination from health care workers impedes service utilization. Violence against women remains relatively common but few linkages exist between HIV services and anti-violence programs.
 - In **Cambodia** the majority of births occur outside medical facilities because of limited opening hours and transportation and financial barriers faced by women. Stigma and discrimination by health care workers was also cited as the reason for high drop-out from the existing program. ARV prophylaxis was not provided to either mothers or infants in 88 percent of births involving an HIV-positive mother. There is limited awareness of vertical transmission services
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even among health care workers, and women are provided with wrong information on infant feeding – with a bias towards formula-feeding. Existing programs are not well integrated into broader health care, and follow-up of women, children and their families is limited.

- In **Moldova** HIV-positive women reported that the quality of pre- and post-testing counselling is very low, and there was a general lack of awareness about vertical transmission, including the risks of mixed-feeding. Lack of budget financing is a barrier to the implementation of the strong commitment to providing HIV services, and there is no gender-specific approach in the national HIV program. Women in rural areas have difficulty accessing care, and half of all of the women surveyed encountered discrimination from health workers.
 - In **Morocco** access to antenatal services is limited and many HIV-positive pregnant women are not identified for lack of HIV testing, especially in rural areas. The fear of stigma and discrimination is a major barrier for women to get tested, both at home and in health care settings. Breast-feeding is contraindicated by the Ministry of Health (an outdated recommendation), but formula is provided in only three cities and only 56 percent of the rural population has access to safe drinking water. Lack of coordination among involved agencies (such as between UNFPA who focus on both maternal and child health and sexual and reproductive health and other UN agencies like UNICEF and UNIFEM) limits their overall effectiveness.
 - In **Uganda** fewer than half of the health facilities that provide antenatal care provide other prevention of vertical transmission services, and options offered at family planning clinics for avoidance of unintended pregnancies are limited. Services are particularly difficult to access in some rural areas and in the post-conflict northern region, and regular ARV stock outs and shortages of health workers, infrastructure and supplies all undermine access. HIV-positive women reported feeling they could afford neither breast-feeding nor replacement feeding because of their own poor nutrition and financial barriers, leading them to more risky mixed feeding. Also HIV-positive mothers are encountering stigma and discrimination at home and from health care workers.
 - In **Zimbabwe** prevention of vertical transmission services were among the best performing HIV programs in the country, but years of economic and political turmoil have led to the collapse of the health system, periodic suspension of services, and unaffordable hospital and transport fees. There is a severe shortage of health care workers and frequent drug stock-outs, and an increasing number of women deliver their babies at home, without antenatal services, post-delivery support or follow-up. Shortage of trained staff also means many pregnant women do not receive sufficient advice on infant feeding. Violence against women has long been among the most significant deterrents to uptake of HIV/AIDS services for women.
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OUR RECOMMENDATIONS

UN agencies were instrumental in helping set the vital goal of universal access to HIV prevention, treatment and care for women, men and children. Their follow-through has been far less notable and effective, however. Persistent inability and unwillingness to collaborate effectively is a key reason for their poor collective performance. They must enhance and improve coordination among themselves and key partners at all levels—global, national and local—as part of a renewed focus on meeting universal access goals. Priority actions aimed at halting vertical transmission include the following:

- UN Secretary-General Ban Ki-moon and the heads of UNAIDS, UNICEF, WHO, the Global Fund and PEPFAR should hold an international summit **to assess global barriers** to scale up vertical transmission services. At this summit, they should clearly and publicly take joint leadership responsibility and recommit their agencies to providing comprehensive vertical transmission services to all women in need. They should also **publish a plan of action** to increase quality coverage.
- At UNGASS in June 2010, UNAIDS, WHO and UNICEF should **measure and report progress** made in preventing vertical transmission based on all four prongs of the UN's comprehensive strategy. Current practice—focusing nearly exclusively on the provision of prophylaxis—is insufficient and no longer acceptable.

All partners involved in meeting targets on preventing vertical transmission must agree on a set of clear priorities and coordinate work to achieve them. However, it is governments who bear the ultimate responsibility for ensuring that their citizens' right to health is upheld. The following are among the specific outcomes that national governments should lead on delivering with the support of donors and UN agencies:

- **Governments should increase access to the most effective triple-dose prophylaxis regimen** to prevent HIV transmission to newborns. Currently, just 8 percent of those treated have access to this regimen; the majority of HIV-positive pregnant women and their infants with access to prophylaxis have no option but to take the far less effective single-dose regimen.
 - **Governments should issue revised national infant feeding policies** that are consistent with global guidelines and latest research. WHO and UNICEF should support this process and also regularly assess implementation of these guidelines in the field and consistently and publicly release results.
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- **Donors and governments should increase funding and implementation prevention programs** specifically benefitting pregnant women, including programmes aimed at reducing violence against women and girls.
 - **UNAIDS, UNFPA and UNICEF should provide technical support to governments to better integrate programs** for the prevention of vertical transmission with sexual and reproductive health and rights, family planning, and maternal and child health.
 - **Governments should revise the program and increase budget allocations in order to treat women, children and families** who are identified as needing ARVs during the course of accessing prevention of vertical transmission services. Far too few women and children are being followed up with the provision of treatment. Globally, in 2007, only 12 percent of women got assessed on the need for treatment and this is a deplorable missed opportunity.
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IMPROVING THE GLOBAL RESPONSE

United Nations agencies and global funding initiatives (such as the Global Fund and PEPFAR) have fundamental responsibility for realizing the potential of comprehensive services to prevent vertical transmission of HIV. These entities must be funders, coordinators, technical advisors and global champions. The research in the six countries covered in this report suggests that although several global entities have made important contributions to delivery of comprehensive services, their individual impacts have been constrained by insufficient linkages and collaboration. Taken together, these fragmented contributions have not led to the kind of robust, consistent programming needed to ensure rapid and sustainable improvements.

It is notable that even though *Missing the Target* researchers asked their diverse set of key informants specifically about the role of global agencies, the response was limited in most countries. This suggests that these global agencies need to be far more visible as advisors and advocates for comprehensive prevention of vertical transmission services that are integrated with HIV, maternal/child health, and sexual and reproductive services. Importantly, UNICEF has launched several high-profile campaigns, including Unite for Children, which includes a primary goal to ensure that appropriate vertical transmission services are available to 80 percent of women in need by 2010. In 2005, UNICEF and WHO convened the first High-Level Global Partners Forum on PMTCT. Such efforts must be expanded, which in turn means the agencies need significantly increased resources to do their important work in the field.

Missing the Target researchers consistently heard of the need for global actors to coordinate their efforts much more closely in the countries where they work. The Interagency Task Team on Children and HIV and AIDS (IATT)¹, led by UNICEF and composed of representatives from UNAIDS co-sponsors, donors, NGOs, academic institutions and other organisations, is charged with helping coordinate policy and programming on the country and global level. Research for this report suggests that the IATT needs to be far more conspicuous and play a more active and aggressive role in the field. IATT should establish a website that serves as a clearinghouse of best practices, partner with health consumers and advocates, and become a more vocal advocate for change globally. In addition, IATT membership must become more transparent and programming must be better informed by the experience of local NGOs working on the ground.

¹ More on IATT at www.unicef.org/aids/index_iatt.html

It is important to note, however, that no matter how or if they change, UN agencies and other global entities can only be as useful as individual governments allow them to be. The agencies serve the governments, which have ultimate responsibility for overseeing service provision for their citizens. Global partners can and should offer extensive support to governments that show a clear interest in developing realistic policies and programmes to reduce vertical transmission.

An example of potentially useful process would be to have Country Coordinating Mechanisms (CCMs) and National AIDS Councils work closely together to assess barriers to care utilization and lay out costed action plans to expand, improve and monitor services. These plans must have both quantitative and qualitative targets, milestones and deadlines. UNAIDS and UNICEF should assess these plans and give feedback to countries on their strengths and weaknesses. All these coordinating bodies – whether working internationally or in affected countries – should include greater representation of the people who are actually meant to use the services. For example, local civil society organizations, including organizations comprised of people living with HIV, should be involved in ongoing advocacy to encourage governments to act more responsibly and consistently, including in regards to addressing stigma, discrimination and violence against women. Such organizations should be supported in building essential watchdog capacity to ensure that governments meet their commitments.

In the area of infant feeding programs there has been an overall failure in terms of coordination of efforts from policy to program level. Although UN guidelines have become relatively clear, global agencies and mechanisms such as PEPFAR and the Global Fund have not been coordinating effectively to implement these guidelines in a consistent manner.

The latest UN guidelines recommend for infants of HIV-infected women exclusive breast-feeding for the first six months of life unless replacement feeding is acceptable, feasible, affordable, sustainable and safe (AFASS) for them and their infants before that time. This report found clear gaps between international infant feeding guidelines, their integration into national policies, and their implementation on the ground. The guidelines have changed over time and some countries need to do more to ensure their policies and program guidelines are up to date. Health care personnel at all levels need additional training to help ensure adequate awareness and to ensure their ability to help health consumers make fully informed choices.

AFASS guidelines are meant to be assessed at an individual rather than a national level, but several reports suggest these assessments are primarily made nationally. Many of our researchers found disproportionate emphasis on the “affordability” piece of AFASS guidelines. Governments should ensure that the full package of child survival and reproductive

health interventions with effective linkages to HIV prevention as well as the AFASS and other conditions contained in the UN guidelines are available before any distribution of free commercial infant formula is considered. Monitoring of infant health is crucial and it is not clear this is being done effectively in many countries.

The best way to ensure that infants are not born with HIV or acquire it during breast-feeding is to provide HIV-positive women the care they need for their own HIV disease. Vertical transmission is certainly an issue where the false dichotomy pitting prevention and treatment against each other is truly nonsense – in studies where HIV-positive women get appropriate care, HIV transmission to infants is largely eradicated². Vertical transmission programs must be linked with HIV treatment programs. The HIV-positive pregnant women most at risk for transmitting HIV to their infants are also the sickest women who are at greatest risk of dying and in most need of treatment for their own health. Their right to health is abridged in the absence of adequate care and treatment.

One of the clearest conclusions from this edition of *Missing the Target* is the significant role that stigma, discrimination and violence play in the lives of many women and the tangible impact of these forces on utilization of care. Such negative phenomena are even more pronounced among HIV-positive women in nearly every society; as such, they require a global response. A well-funded and coordinated effort is needed to test and then bring to scale the most effective responses to address these issues. One priority is to support programs and then measure progress in reducing stigma and discrimination specifically in health care settings.

The research in this report suggests many opportunities for global agencies, national governments, and major donors to improve the reach and effectiveness of prevention of vertical transmission services. The recommendations proposed in the Executive Summary focus on some of the initial, priority action steps and interventions.

2 Townsend, C.L., Cortina-Borja, M., Peckham, C.S., De Ruiter, A., Lyall, H., Tookey, P.A. Low rates of mother-to-child transmission of HIV following effective pregnancy interventions in the United Kingdom and Ireland, 2000-2006 (2008) AIDS, 22 (8), pp. 973-981.