



MISSING THE TARGET

7

Failing Women,  
Failing Children:  
*HIV, Vertical  
Transmission and  
Women's Health*

On-the-ground research in Argentina, Cambodia,  
Moldova, Morocco, Uganda, Zimbabwe

May 2009

**The International Treatment Preparedness Coalition (ITPC)**

is a worldwide coalition of people living with HIV and their supporters and advocates. Its overall goals and strategies are signalled in its mission statement:

**Using a community-driven approach to achieve universal access to treatment, prevention, and all health care services for people living with HIV and those at-risk.** As of the end of 2008, thousands of individuals in 125 countries were directly affiliated with ITPC and working to achieve these goals at the local, regional and international levels.

**The Treatment Monitoring & Advocacy Project (TMAP)**, a project of ITPC, identifies barriers to delivery of AIDS services and holds national governments and global institutions accountable for improved efforts. The *Missing the Target* series of reports remains unique in the world of AIDS and global health, offering a comprehensive, objective, on-the-ground analysis of issues involved in delivery of AIDS services that is “owned” by civil society health consumers themselves.

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## TABLE OF CONTENTS

Acknowledgements	ii
Acronyms and Abbreviations	iii
Preface	iv
Executive Summary	1
Improving the Global Response	9
Country Reports	
● Argentina	15
● Cambodia	24
● Moldova	35
● Morocco	45
● Uganda	56
● Zimbabwe	66

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## ACKNOWLEDGEMENTS

### RESEARCH TEAMS

#### Argentina

##### General coordination and

**report author:** Lorena Di Giano

**Interviews:** Lorena Di Giano, Pablo García, and Alcira González

#### Cambodia

Dr. Kem Ley, freelance consultant on HIV and health; and Umakant Singh, Norton University

#### Moldova

##### General coordination and

**report author:** Liudmila Untura, Childhood for Everyone

**Interviews:** Igor Chilcevchii, League of PLWHA in Moldova Republic; Igor Moiseev, Credinta; Natali Mordari, Childhood for Everyone; Vladlena Semeniuc, League of PLWHA in Moldova Republic

#### Morocco

Othoman Mellouk, Association de Lutte Contre le SIDA (ALCS), Marrakech; and Nadia Rafif, CSAT regional coordinator for MENA region

#### Uganda

Richard Hasunira, Coalition for Health Promotion and Development (HEPS)-Uganda

Aaron Muhinda, HEPS-Uganda  
Rosette Mutambi, HEPS-Uganda  
Beatrice Were, HIV/AIDS activist

#### Zimbabwe

Matilda Moyo, Pan African Treatment Access Movement (PATAM)

Caroline Mubaira, Community Working Group on Health (CWGH), Southern African Treatment Access Movement (SATAMo), and PATAM

Martha Tholanah, Network of Zimbabwean Positive Women (NZPW+), SATAMo, PATAM and ITPC

### COORDINATION

#### Project coordinators

Maureen Baehr, Chris Collins, Gregg Gonsalves, Aditi Sharma

#### Editing

Jeff Hoover

#### Research and editorial support

Erika Baehr

#### Communications support

Attapon Ed Ngoksin

#### Media support

Brett Davidson

Kay Marshall

gabbegroup Public Relations &

Marketing: Jill S. Gabbe, Jennifer

Robinson, Olivia Goodman, and

Caitlin Hool

#### Design

Pamela Hayman

#### Missing the Target 7 Advisory Committee

Mabel Bianco, Ellen Brazier, Padma

Buggineni, Polly Clayden, Francois

Dabis, Pascal Daha Bouyom, Paula

Donovan, Cynthia Eyakuze,

Kevin Fisher, Glenda Gray, Julia

Greenberg, Sofia Gruskin, Anu Gupta,

Lida Lhotska, Alessandra Nilo, and

Caleb Orozco

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### CONTACT INFORMATION

Project coordination:

Aditi Sharma

[aditi.campaigns@gmail.com](mailto:aditi.campaigns@gmail.com)

Gregg Gonsalves

[gregg.gonsalves@gmail.com](mailto:gregg.gonsalves@gmail.com)

ITPC secretariat:

[attapon@apnplus.org](mailto:attapon@apnplus.org)

Website:

[www.itpcglobal.org](http://www.itpcglobal.org)

## ACRONYMS AND ABBREVIATIONS

The following acronyms and abbreviations may be found in this report:

<b>AFASS</b> = acceptable, feasible, affordable, sustainable, safe	<b>NAP</b> = National AIDS Program	<b>UNFPA</b> = United Nations Population Fund
<b>ANC</b> = antenatal care	<b>NCHADS</b> = National Centre for HIV/AIDS, Dermatology and STDs (Cambodia)	<b>UNGASS</b> = United Nations General Assembly Special Session
<b>ART</b> = antiretroviral treatment	<b>NGO</b> = non-governmental organization	<b>UNICEF</b> = United Nations Children's Fund
<b>ARV</b> = antiretroviral	<b>NMCHC</b> = National Maternal and Child Health Centre (Cambodia)	<b>UNIFEM</b> = United Nations Development Fund for Women
<b>CCM</b> = Country Coordinating Mechanism (Global Fund)	<b>OI</b> = opportunistic infection	<b>VCT</b> = voluntary counselling and testing
<b>CDC</b> = US Centers for Disease Control and Prevention	<b>PCR</b> = polymerase chain reaction	<b>WHO</b> = World Health Organization
<b>DFID</b> = UK Department for International Development	<b>PEPFAR</b> = US President's Emergency Program for AIDS Relief	Note on text: All "\$" figures are US dollar amounts, unless otherwise specified.
<b>EGPAF</b> = Elizabeth Glaser Paediatric AIDS Foundation	<b>PITC</b> = provider-initiated testing and counselling	
<b>ELISA</b> = Enzyme-linked immunosorbent assay	<b>PLWHA</b> = people living with HIV/AIDS	
<b>Global Fund</b> = Global Fund to Fight AIDS, Tuberculosis and Malaria	<b>PLHIV</b> = people living with HIV	
<b>IDU</b> = injecting drug user	<b>PMTCT</b> = prevention of mother-to-child transmission	
<b>IEC</b> = information, education and communication	<b>PMTCT+</b> = prevention of mother-to-child transmission plus	
<b>MoH</b> = Ministry of Health	<b>PPTCT</b> = prevention of parent-to-child transmission	
<b>MCH</b> = maternal and child health	<b>SOP</b> = standard operating procedure	
<b>MDGs</b> = Millenium Development Goals (UN)	<b>SRH</b> = sexual and reproductive health	
<b>MSM</b> = men who have sex with men	<b>STD</b> = sexually transmitted disease	
<b>NAA</b> = National AIDS Authority	<b>STI</b> = sexually transmitted infection	
<b>NAC</b> = National AIDS Council	<b>TB</b> = tuberculosis	
	<b>UN</b> = United Nations	
	<b>UNAIDS</b> = Joint United Nations Programme on HIV/AIDS	
	<b>UNDP</b> = United Nations Development Programme	

## PREFACE

Six months ago, the researchers and activists involved in this report set out to understand why the world is missing the target on a goal it set back in 2001: to reduce the rate of HIV infections from mothers to babies by half. What emerged was evidence that the global institutions in charge have been cooking the statistical books. Despite the success they've proclaimed, they're nowhere near the target. They haven't even been aiming for it.

On paper, the global program called 'Prevention of Mother-to-Child Transmission' is a model of sound design and human rights principles. Its four prongs cover the gamut from prevention to counselling to treatment.

In practice, the program is a shameful example of double standards.

We remember well the elation in the mid-90s at our former office in UNICEF headquarters, when results emerged from clinical trials in Uganda and Thailand. The risk of vertical transmission – passage of the virus from one generation to the next – could be slashed, thanks to simple, relatively low-cost drug regimens for mothers and infants. An 11-country pilot project was spearheaded by UNICEF and assisted by the World Health Organization, and the good news/bad news rollercoaster ride began.

The first low point came with the pilot projects' title: Prevention of Mother-to-Child Transmission, or PMTCT – a name that implies that

mothers are the source of the virus, rather than the latest link in a long chain of transmission.

In 2000 came good news: the pharmaceutical company Boehringer Ingelheim announced that for the next five years, any developing country could request free supplies of its antiretroviral drug nevirapine – a single dose of which, administered during labour to an HIV-positive woman and immediately after birth to her baby, was then believed to cut by half the risk of transmission (now we know that it's actually two-fifths). Buoyed by the possibilities, the world's governments made a commitment in 2001 to reduce infant infections by 20 percent by 2005, and 50 percent by 2010.

Suddenly, silence. For years, in report after report issued by UNAIDS, the global Prevention of Mother-to-Child Transmission program barely got an honourable mention. By 2003, 95 percent of the HIV-positive pregnant women in sub-Saharan Africa, the pandemic's epicenter, were not receiving any services at all to prevent vertical transmission. UNICEF went back and forth on infant feeding. Like so many other programs targeting women, everyone and no one at the UN seemed to be in charge. Wealthy nations were bringing their transmission rates down to negligible levels. Overall, for poor women in developing countries, coverage stalled at 9 percent as rates of paediatric infection soared. Scale-up was slow, uptake was low, and no one seemed to know why. Experts offered reasons: women

refuse testing; women don't return for test results; women given drugs to self-administer don't take them properly. The problems, it seemed, were caused by the women.

In the meantime, researchers were concluding that for most of the world's babies born to mothers with HIV, the best guarantee of HIV-free survival at a year and a half was a diet of nothing but breastmilk for the first six months. But most women didn't breast-feed exclusively. The UN's ardour for explaining breast-feeding to women had diminished as the issue became more complex: babies needed to be fed all breastmilk, or all breastmilk replacements such as formula; mixing the two could kill them. Before a mother chose not to breast-feed, she'd first need to assess whether for her, replacements met five criteria: acceptable, feasible, affordable, safe and sustainable (AFASS). And then the most difficult risk to weigh: without the nutrients and immunities in mother's milk, the baby could die of other causes. Before long, in developing countries that provided formula and encouraged women with HIV to avoid breast-feeding, many babies did die.

About two years ago, we began to notice a triumphant tone in reports of vertical transmission from global agencies. All heralded the fact that coverage was finally climbing.

In 2008, cautiously optimistic, AIDS-Free World accepted an invitation to join TMAP in its own assessment.

What we've learned since has been eye-opening and deeply disturbing. We should have seen it coming: after all, what HIV-related program that deals specifically with women has not lacked funds, urgency, coordination, and a place on the list of global and national priorities? Isn't this precisely why we've been advocating for the new women's agency the UN so desperately needs? What we didn't expect to find, though, was a conspiracy of misinformation.

"There has been substantial progress in scaling up access to services for the prevention of mother-to-child transmission," boast WHO, UNAIDS and UNICEF in a 2008 progress report called *Towards Universal Access*.

'Progress' is expressed thus: in 2007, 33 percent of pregnant women living with HIV in developing countries received drugs to block transmission to their children.

The research conducted for *Missing the Target 7* by teams in six countries corroborates the ugly truth: the much-touted coverage of 33 percent consists primarily of women who received nevirapine, in regimens that reduce the risk of HIV transmission by only about two-fifths, and can cause resistance to the drug in women who may need it at a later stage of their own HIV disease. Very few received the triple combination therapy that has helped make vertical transmission virtually a thing of the past in the global North.

By and large, the 33 percent represents women who didn't get contraceptives or other support to avoid future unintended pregnancies. What's more, they weren't counselled about infant feeding (or worse, got wrong information), and were encouraged not to breast-feed because, with free supplies of formula, they met *one* of the five conditions: affordable. And, in a direct assault on women's rights as human beings rather than just mothers, most were sent home before anyone bothered to find out if they needed antiretroviral drugs for their *own* health.

In other words, 'substantial progress' in this four-pronged program is determined by ticking off any woman who gains access to just one part of one prong.

Was this minimalist, inequitable program effective at all? Did it move the world any closer to its goal of halving infections in infants by 2010? Hard to tell, since only 8 percent of the babies born to pregnant women with HIV in 2007 were tested for HIV by two months of age.

One fact, however, is unequivocally clear: the women who receive 'PMTCT' services as they're comprehensively defined amount to far, far fewer than 33 percent.

We reject the double-talk that touts failure as success, and the double standard that values wealthy women over poor. There is a crying need for an honest global evaluation to measure progress

against each of the four prongs and every one of the guiding principles. Instead of trumpeting a sham triumph, the institutions involved should initiate such an evaluation, see which agency is responsible for which shortfall, and draft a time-bound plan to shape up. Women would be better served if the entire program were taken apart and put back together in a realistic way, keeping in mind that platitudes do not keep women and babies alive and healthy.

We sincerely hope that the promised UN women's agency will ensure that prevention of vertical transmission is the last in a disgracefully long line of initiatives for women to fall through the gender-impervious cracks of the UN system.

*Stephen Lewis and  
Paula Donovan*  
Co-Directors, AIDS-Free World





*“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

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VERTICAL TRANSMISSION OF HIV (commonly known as mother-to-child transmission)<sup>1</sup> 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.

<sup>1</sup> 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 to 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

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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)<sup>1</sup>, 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.

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<sup>1</sup> More on IATT at [www.unicef.org/aids/index\\_iatt.html](http://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

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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 eradicated<sup>2</sup>. 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.

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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.



# Country Reports

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# Argentina

**General coordination:** Lorena Di Giano, AIDS activist

**Interviews:** Lorena Di Giano, Pablo García, and Alcira González

**Report author:** Lorena Di Giano

## KEY POINTS

1. No specific gender-based HIV prevention strategies exist within the government's HIV prevention program.
2. Disparities occur around Argentina in terms of health care availability and quality. In some cities fewer than 70 percent of pregnant women take an HIV test prior to going into labour, despite a national policy for all pregnant women to be offered HIV testing.
3. Health professionals reportedly place disproportionate priority on children's rights over those of women, and women often receive inadequate information about their own rights, including that of informed consent and the provision of appropriate counselling before and after HIV testing.
4. UN agencies at the global level should coordinate more effectively and consistently with UN country offices to implement and promote international recommendations at country level.

## RESEARCH PROCESS AND METHODOLOGY

Research for this report was conducted from November 2008 to January 2009. It consisted of an extensive review of documents and websites from governmental and non-governmental sources; in-depth interviews based on semi-structured questionnaires; and two focus groups. One focus group comprised five health care workers, while the other was composed of four HIV-positive mothers, one of whom was pregnant at the time.

A total of 23 people were interviewed in six cities across Argentina: Buenos Aires, Mar del Plata, Montegrande, Rosario, Tres Arroyos, and Tucumán. They included representatives from UN agencies (UNAIDS, UNFPA and UNICEF); national AIDS authority staff; local AIDS program managers; health workers (paediatricians, psychologists, social workers, nurses and prevention of vertical transmission specialists); human rights advocates; women living with HIV; health care users living and not living with HIV; and a manager of a home for HIV-positive children.

## 1. BACKGROUND INFORMATION

According to government estimates released in August 2008, about 134,000 HIV-positive individuals currently live in Argentina. Of those, about half are thought to be unaware of their status. Women comprise approximately one quarter of all people living with HIV, with the majority of cases among women aged 30 to 39.

Between 1986 and 2007, a total of 3,857 individuals under 14 years of age were diagnosed with HIV. The annual number of new HIV cases among infants and children began to decline in 2002 following the implementation of a national coordinated prevention of vertical transmission policy. Of the 1,493 reported cases of HIV infection among people under age 14 diagnosed between 2001 and 2007, 92 percent were attributed to vertical transmission, 1 percent to blood transfusions and 1 percent to other causes. (The transmission cause was unknown or unclear in the remaining 6 percent of cases.)

*“Adherence is possible even in the worst socio-economic context. We should continue expanding antiretroviral treatment for all populations.”*

Local AIDS program manager,  
Rosario city

## **2. STATUS OF SERVICE DELIVERY AMONG AND FOR WOMEN**

### **PRIMARY PREVENTION AMONG WOMEN**

Limited data exist in Argentina as to the main HIV risk and vulnerability factors for women<sup>1</sup>. This is mainly due to the fact that there are no specific gender-based HIV prevention strategies within the government’s HIV prevention program; instead, messages and interventions are common to all populations.

Pregnant women are the key focus of HIV prevention efforts among women. This effort is helped by the fact that most women begin to access health care during pregnancy.

### **REPRODUCTIVE HEALTH NEEDS OF WOMEN LIVING WITH HIV**

As noted through the research, a core demand of women living with HIV is increased access to contraceptives and other materials that can help increase their control over their reproductive lives. They also want better access to family planning counselling and sexual and reproductive rights information as part of routine health care.

Recent steps appear to have been taken to address these needs. With the support of UNFPA, the national AIDS authority is seeking to reinforce prevention of vertical transmission interventions by developing a set of guidelines that will contain recommendations for counselling, care and other interventions for women and their sexual partners. These guidelines will also refer to specific sexual and reproductive health needs of women living with HIV. The authority plans to finalize the guidelines by mid-2009.

### **PREVENTION OF HIV TRANSMISSION FROM MOTHER-TO-CHILD**

In general, pregnant women’s access to HIV testing is high due to the implementation in 2001 of a national policy mandating that all pregnant women be offered an HIV test at the first level of health care. However, one result of Argentina’s federal system is that there are great disparities around the country in terms of health care availability and quality, including in regard to prevention of vertical transmission coverage and services. In some cities fewer than 70 percent of pregnant women take an HIV test prior to going into labour<sup>2</sup>. According to the national AIDS authority, persistent limitations in HIV testing coverage in some regions and areas (especially outside the major urban areas) are related to bureaucratic inefficiency and deficient logistics systems.

1 A recent study on female sex workers is an exception: “Estudio social en trabajadoras sexuales: Saberes y estrategias de las mujeres trabajadoras sexuales ante el VIH/SIDA y otras ITS”, EMIGT team, CEIL-PIETTE/CONICET, final report released December 2007.

2 Differences persist across the country in terms of share of women who are tested for HIV during pregnancy. The percentage is highest (and thus above 70 percent) in major urban areas such as Buenos Aires and Mar del Plata.



Other research findings include the following:

- There was a general agreement among respondents that the most important challenge regarding prevention of vertical transmission is the fact that many pregnant women do not visit health centres until relatively late in their terms. This is particularly true in communities isolated by geography and characterized by relatively low income and education levels<sup>3</sup>.
- Rapid HIV tests are available in more than three quarters of Argentina's 24 provinces. However, findings indicate an urgent need to build appropriate capacity among health workers in order to optimize clients' opportunity to access this testing mechanism.
- Antiretroviral prophylaxis for use during pregnancy, labour and delivery is widely available across the country. Most respondents agreed that although adherence to prophylaxis is relatively high, it is certainly not universal. Therefore, more energy should be invested in creating and promoting programs that focus on treatment literacy and adherence, as well as on reinforcing psychological and social support offered during pregnancy.
- One important impact from the scale-up of prevention of vertical transmission services has been an improvement in the scope and quality of other services for pregnant women. Such improvements include the capacity for early diagnosis of other STIs, increased priority given to pregnant women in health care settings in general, and enhanced availability and accessibility to a comprehensive range of antenatal care services in several jurisdictions. The overall result has been an increase in inclination and ability among all pregnant women to obtain health care during and after pregnancy.
- In general, the expansion of prevention of vertical transmission strategies has not been accompanied or followed by an increase in human resources. This means that existing health workers have far more duties and responsibilities, thereby compromising their capacity to provide thorough and appropriate care and services in many instances.

### **PROVISION OF SERVICES FOR HIV-POSITIVE MOTHERS, THEIR PARTNERS AND THEIR FAMILIES**

The findings of the research indicate that policymakers recognize the need for a comprehensive approach to prevention of vertical transmission services that includes not only HIV-positive mothers but their partners and close relatives. Priorities in many settings include post-partum adherence to treatment by HIV-positive mothers as well as infant follow-up, care and treatment provision.

<sup>3</sup> Missing the Target # 6: The HIV/AIDS response and health systems: Building on success to achieve health care for all, Argentina country report, July 2008, p. 12.

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Research indicates that in most facilities the identification of HIV infection among women in prevention of vertical transmission programs is used as an entry point to recommend HIV testing and counselling to other family members. However, all respondents noted that the number of sexual partners who make use of these services is still extremely low.

The MoH has begun promoting a new program in certain jurisdictions with the goals of providing more accurate and comprehensive care for pregnant women, their children and couples; securing early diagnosis and treatment to prevent vertical transmission of syphilis; and stimulating greater uptake of HIV testing. The components of this program are aimed at reinforcing HIV prevention interventions.

### **PROVISION OF SERVICES FOR INFANTS AND CHILDREN LIVING WITH HIV**

Although the number of new infections among children has decreased sharply over the past several years (as noted previously in this report), greater efforts are needed to ensure that progress continues. Most cases of HIV infection among infants and children stem from insufficient information and counselling provision among women in regards to HIV/AIDS and sexual and reproductive rights and the lack of adequate antenatal care during pregnancy. Respondents consider all new cases to be inexcusable given the broad prevention mechanisms currently available.

Universal free access to treatment and care for HIV-positive people is guaranteed by law in Argentina. According to some respondents, however, this guarantee has proved meaningless at times because paediatric formulations of ARVs are often not available on a regular basis. The government blames such shortcomings on the limited number and type of such formulations on the global market.

In regards to the provision of other services for HIV-positive children, respondents said there is an urgent need to develop practical standardized protocols in non-medical areas as well. Such protocols ideally would include guidelines for health care personnel in regards to discussing issues such as disclosing HIV status and managing treatment adherence among children. Strategies are also needed to overcome challenges related to older children's passage to adolescence and adulthood, milestones that require new and different types of care.

In general, a more comprehensive approach is needed. The promotion of networks between health care providers at local levels and more centralized HIV/AIDS reference centres would provide the protective environment children and their families need. Policies should be more focused on social necessities in terms of treatment and care, such as covering transportation costs, responding to nutritional needs, and promoting better levels of adherence.

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*“Many pregnant women cannot find the time or money to seek the highest quality care even when it is available free of charge. For example, one woman recently told me, ‘Doctor, I already have four other children and I can’t go to the health centre very easily.’”*

Local AIDS program manager,  
Mar del Plata

## **BARRIERS TO COMPREHENSIVE SERVICE DELIVERY AND LESSONS LEARNED**

Lingering HIV-related stigma and discrimination – especially at the provincial level and in small communities – remains an obstacle that many PLWHA face in regards to access to comprehensive HIV/AIDS human rights information, prevention, treatment, care and support. Other major problems include excessive bureaucratic requirements that frustrate easy and timely access to routine diagnostics (CD4 and viral load tests) and poorly performing drug logistics and supply systems in some jurisdictions.

Some health professionals place disproportionate priority on children’s rights over those of women in prevention of vertical transmission interventions. This means that some women receive inadequate information about their own rights, including that of informed consent and the provision of appropriate counselling before and after HIV testing. Researchers also found that in many facilities, counsellors only provide HIV information to women when test results are positive.

The following are among the lessons learned in the ongoing effort to bring a comprehensive set of services to scale in Argentina:

- More extensive information-sharing and networking between primary health care facilities and ART centres have helped to scale up access to comprehensive HIV treatment, care and support services, including those related to prevention of vertical transmission, among women living HIV.
- Improved integration of prevention of vertical transmission programs with services to prevent and treat other STIs (e.g., a program to control congenital syphilis) has increased opportunities for women and their families to access HIV counselling and testing services.
- The use of HIV-positive mothers as peer counsellors in prevention of vertical transmission centres has improved provision of care and support as well as increased pregnant women’s confidence in public services.

## **3. HIV TESTING: ACCESS AND OTHER ISSUES**

General HIV testing policy in Argentina follows the traditional model of client-initiated voluntary counselling and testing (VCT). According to official regulations, VCT should be provided freely at reference centres and comply with three principles: i) *informed consent*, which refers to an individual’s right to agree or not agree to be tested only after being provided with extensive information about what the test means; ii) *pre- and post-test counselling*, which should include the provision of HIV prevention and care information; and iii) *confidentiality* on the part of health care personnel in regards to not only the test results but the actual fact that the testing itself took place.

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The provider-initiated testing model for pregnant women has been in place since 2001, as part of the national prevention of vertical transmission policy. Under this model, pregnant women are offered HIV testing in all settings at the first level of care. This MoH-recommended strategy, which is based on the importance of early detection of HIV, calls for an initial test during the first three months of pregnancy and a follow-up test during the final trimester. Standard ELISA tests are currently used in most cases; the use of rapid tests is only indicated in cases where the mothers in labour have not yet been tested for HIV.

HIV-positive women respondents said they generally feel comfortable disclosing their status and discussing it openly in health care settings. Managers of HIV testing reference centres acknowledged the ongoing challenge of ensuring confidentiality in small communities where health care workers and patients are more likely to share friends, family members, etc.

Current national laws protect the right of adolescents to seek out and be tested for HIV on their own. Respondents in many health centres said, however, that parental authorization is often requested for those under the age of 21. This practice goes against the basic rights of adolescents to privacy and confidentiality and constitutes an important barrier that should be removed.

According to the findings, there is also a need to focus more on integrating HIV testing and counselling in primary health facilities, build capacity among health care workers in order to optimize information and counselling provision, and ensure confidentiality of HIV test results. Several respondents also recommended improving efforts to help women manage 'guilty feelings' about the possibility of transmitting HIV to their babies; to prepare them for disclosing HIV-positive results to their partners and relatives; and to face and withstand potential HIV-related stigma and discrimination.

The issue of 'guilty feelings' is encapsulated in the following quote from an HIV-positive woman interviewed in Mar del Plata: "When I was diagnosed I was in the third month of my pregnancy. My first reaction was fear—of transmitting the virus to my son....I cried a lot even after my doctor told me the treatment was almost certainly going to be effective. This feeling of fear and concern was present until I gave birth. Luckily my son is not infected."

#### **4. INFANT FEEDING GUIDELINES AND TRENDS**

The government's national policy recommends that HIV-positive mothers do not breast-feed their newborns. Counselling is provided to mothers so they can make informed decisions about whether or not to follow this recommendation. The cost of formula is not usually a factor in such decisions because replacement feeding is available free of charge

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and accessible across the country to women in need, and is distributed through the national procurement chain. Advocates note, though, that stock-outs of formula are occasionally reported. PLWHA networks play a major role in monitoring stock-outs and subsequently demanding that the government respond immediately to address the shortfalls.

Most health care facilities provide extra counselling and psychosocial support for HIV-positive mothers as part of an effort to counter a strong cultural tradition in favour of breast-feeding. Respondents report that such efforts have been largely successful and that adherence to replacement feeding is high.

*“In our country it’s not incorporated in the practice of health care centres that women living with HIV can or should plan their pregnancies.... Family planning is not considered a routine offering.”*

**UNFPA representative in Argentina**

## **5. IMPACT OF VIOLENCE AND STIGMA**

The Argentinean government has repeatedly declared its commitment to improve the status of women and to eliminate discrimination and violence against them. However, a recent report<sup>4</sup> on gender violence indicates that violence against women remains relatively common within many families and in many communities<sup>5</sup>. Some of the blame can be placed on tradition and culture, but at the same time the government has done far too little to address the problem. No extensive official data exist as to the magnitude and characteristics of violence against women, and the weak and limited public policies in place have proved ineffective in safeguarding women’s rights and safety from abuse.

The vulnerability of most women is increased by the lack of employment and economic opportunities available to them in comparison with men, and sexism is ingrained in the male-dominated police and judiciary systems. Such economic and social barriers limit women’s freedom and autonomy in all respects, including in regards to their ability to take care of themselves and their children.

Vulnerability is increased when a woman is diagnosed with HIV (often during pregnancy) and then must inform her partner and/or family members. Such disclosures can prompt violent reactions related not only to the HIV itself but to other sensitive issues such as infidelity and sex in general.

HIV/AIDS service providers have yet to respond adequately to either the threat or reality of HIV-related violence against women. Few linkages exist between HIV services and anti-violence programs in general.

4 Amnesty International in Argentina: “Muy Tarde, Muy Poco”, November 2008.

5 Statistics published by Amnesty International show that in the first 10 months of 2008, at least 110 women in Argentina were killed by a family member, a partner or a former partner.

## 6. ASSESSING THE WORK OF GLOBAL AGENCIES

The support of international donors and agencies has been crucial in terms of improving HIV/AIDS services for mothers and children in Argentina. Major scale-up, especially in prevention of vertical transmission services, began in 1997 with the implementation of a project (named LUSIDA) financed by the national MoH and the World Bank. Those efforts have been reinforced with the support of Global Fund grants awarded more recently.

There is substantial room for improvement on the part of UN agencies. For example, it would be helpful if UN agencies at global level coordinated more effectively and consistently with UN country offices to implement and promote international recommendations at country level. Country officials are often unfamiliar with global guidance produced by UN agencies at the international level.

UN agencies should reconsider the decision to eliminate UNAIDS Theme Groups at the country level. These decision-making spaces within the UN system provide important opportunities for UN agencies, government representatives and civil society representatives to identify and develop responses to the real HIV-related priorities at country level.

All global agencies should also redouble their efforts to include and/or maintain the involvement of local civil society in all country-level processes.

### RECOMMENDATIONS

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**National and local health authorities should work together and in partnership with civil society – including people living with HIV – to:**

- undertake operational and other research to i) identify factors that increase women's and children's vulnerability to HIV infection, and ii) continuously improve the comprehensiveness of prevention of vertical transmission programs;
  - develop gender-based HIV/AIDS prevention programs that focus on the specific risk factors and needs of women;
  - incorporate PLWHA-provided peer counselling in all strategies and programs related to prevention of vertical transmission;
  - include sexual and reproductive health care and family planning as essential interventions for HIV prevention, care and treatment;
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- place greater priority on including women from the most at-risk groups in designing, implementing and monitoring HIV/AIDS service programs. Such efforts will help make prevention and treatment more readily available, accessible and acceptable for all women in need;
- improve logistics and supply systems for replacement feeding for HIV-exposed infants in order to prevent stock-outs;
- review current infant feeding guidelines for HIV-positive women with the goal of updating them in accordance with the latest international WHO recommendations; and
- integrate HIV testing and counselling in all of the country's primary care facilities and eliminate all barriers that prevent children and adolescents from seeking HIV testing, treatment, care and support services in a confidential manner.

**In partnership with civil society and with the support of global agencies, the MoH should work with other ministries (at the national and local level) to develop human capacity at all levels through training in order to:**

- reduce HIV-related stigma and discrimination;
- ensure compliance with the principles of informed consent and confidentiality;
- promote greater awareness and sensitivity to human rights and gender-specific issues among health workers;
- improve the quality of HIV information and counselling provision;
- enhance coordination between HIV/AIDS services and anti-violence referral services; and
- promote treatment literacy among women and children living with HIV.

**Civil society should:**

- improve its capacity to monitor HIV-related policies and programs at national and local level; and
- enhance its capacity to develop and implement advocacy strategies and facilitate policy change in all HIV-related priority areas.

**Global agencies should devote more energy and resources to:**

- galvanize political will and mobilize resources to reach the goal of universal access to comprehensive HIV prevention, treatment, care and support for women and children.
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# Cambodia

By Dr. Kem Ley, freelance consultant on HIV and health, and Umakant Singh, Norton University

## KEY POINTS

1. Policies, guidelines, and a strategic plan are in place in Cambodia to meet the UN's four-pronged strategy to prevent vertical transmission, however, practical application has been limited.
2. The majority of births (78 percent) occur at home or outside public health facilities in which prevention of vertical transmission services are available. As a result, the vast majority of women of childbearing age miss the opportunity to be tested for HIV.
3. Access to prevention of vertical transmission services is hindered by poor integration with broader health care services, most notably key maternal and child health services.
4. Health care providers are directed to provide all mothers with information on the potential risks and benefits of all forms of feeding; however, many public-sector and civil society personnel reportedly are heavily biased in favor of the formula feeding option.

## RESEARCH PROCESS AND METHODOLOGY

This report is based on i) a desk review of documents including the National Strategic Plan for PMTCT 2008-2015, the national prevention of vertical transmission guidelines from 2005 and the 2007 Cambodia PMTCT Program Joint Review Report; and ii) a total of 25 interviews with key informants. Interviews were conducted with government representatives (10 individuals total) from the National Maternal and Child Health Centre, the National AIDS Authority, the National Centre for HIV/AIDS Dermatology and STIs, and the Takeo Provincial Health Department; one person each from three UN agencies (UNAIDS, UNFPA and UNICEF); eight representatives of international and local NGOs, including ActionAid International, Care, World Vision, Family Health International, HIV/AIDS Coordinating Committee, the Cambodian Community of Women Living with HIV/AIDS, and the Cambodian People Living with HIV/AIDS Network; and four individuals associated with a private-sector maternity and a children's hospital. Researchers also conducted a roundtable discussion with 25 midwives and held two focus group discussions with pregnant women, one in an urban area at Takeo Health Centre (10 women), and one in a rural area at Samrong Health Centre (12 women).

## 1. BACKGROUND INFORMATION

Estimated HIV prevalence among adults (15 to 49 years of age) in Cambodia has declined from a peak of 2.3 percent in 1997 to about 0.9 percent in 2006. Projections indicate that, if interventions are sustained at current levels, HIV prevalence will further decline before stabilising at 0.6 percent by 2011. However, a resurgence of the epidemic cannot be ruled out given the relatively high prevalence among most at-risk populations, including female sex workers, their clients and other sexual partners; men who have sex with men (MSM); and injecting drug users (IDUs). For example, a study in 2008 conducted by the MoH and the Ministry of Interior indicated that HIV prevalence among IDUs is 24.4 percent.

Based on new HIV prevalence estimates and projections, the number of people living with HIV (PLHIV) was estimated at 64,750 (including 3,350 children under the age of 15) in 2007. Some 29,200 adults were in need of antiretroviral therapy (ART), a number that is expected to increase to 35,100 by 2010.

Cambodia's prevention of vertical transmission program was started in 2000 with the formation of a national technical working group and prevention of vertical transmission secretariat at the National Maternal and Child Health Centre (NMCHC). Since then there has been a gradual increase in the percentage of HIV-positive pregnant women who receive ART to reduce the risk of vertical transmission; that share increased from



7 percent in 2004 to 14 percent in 2007. Meanwhile, estimated vertical transmission declined from 30.5 percent of all births to HIV-positive women in 2001 to 11.4 percent in 2007<sup>6</sup>.

In 2007, the prevention of vertical transmission program tested and provided pre- and post-test counselling to 16.1 percent of Cambodia's pregnant women. It also provided ARV prophylaxis to 11.2 percent of the estimated total number of HIV-positive pregnant women and later to their newborns. The low level of coverage is highlighted by the fact that 83.9 percent of all Cambodian pregnant women in 2007 did not know their HIV status and no ARV prophylaxis was provided to either mothers or infants of 88 percent of births involving an HIV-positive mother.

As of September 2008, there were 154 sites and 76 operational districts with at least one health centre providing prevention of vertical transmission services.

## 2. STATUS OF SERVICE DELIVERY AMONG AND FOR WOMEN

*“With PMTCT policy, strategic plan, SOPs and guidelines, we have the foundation for a scaled response, and we are confident in achieving the universal access target for PMTCT in 2010.”*

**Tony Listle, UNAIDS  
country representative**

Several different government agencies share responsibility for HIV/AIDS services of importance to women. NMCHC implements prevention of vertical transmission intervention within its maternal and child health (MCH) services unit; the National Centre for HIV/AIDS, Dermatology and STDs (NCHADS) provides VCT, ART and OI services; and the National AIDS Authority (NAA) has a national coordination and resource mobilization role.

The prevention of vertical transmission program has benefited from money provided through Rounds 4 and 7 of the Global Fund as well as various UN agencies, bilateral agencies (notably those of the United Kingdom and the United States), and international and national NGOs. (Cambodia was hoping to use resources from the Global Fund's Round 8 to further scale up the PMTCT program, but the country's proposal for that round was denied. A new proposal is being prepared for consideration for Round 9 funding.)

The Cambodian prevention of vertical transmission policy and strategic plan 2008-2015 requires that services be based on the UN's four-prong strategy<sup>7</sup>. The policies, guidelines and standard operating procedures for all of the prongs are in place in Cambodia, but practical application has been limited. As observed by some NGO respondents, “Everything is clear on paper, but not in implementation.”

6 Towards Universal Access report 2008, UNAIDS and WHO.

7 Additional information about the UN's four-prong strategy may be found online at [www.unicef.org/aids/index\\_preventionyoung.html](http://www.unicef.org/aids/index_preventionyoung.html).

Members of the Cambodia country team developed a scorecard, based on a scale of A to D<sup>8</sup>, to measure each of the four prongs' availability and implementation to date. The results are as follows:

1. Primary prevention of HIV infection (Prong 1): B+. Many institutions, including the NAA, UN agencies and NGOs, focus on primary prevention among the general population, but few programs specifically target women and girls. The Ministry of Women Affairs' strategic plan for the prevention of HIV/AIDS among women and girls 2008-2012 intends to address the gap by increasing primary prevention among women and girls.
2. Prevention of unintended pregnancies among HIV-positive women (Prong 2) is weakest and can be given a C. The main reason is lack of positive prevention programs and insufficient access to condoms. However, the revised National Strategic Plan for Comprehensive and Multispectral Response to HIV/AIDS (2008-2010) focuses on positive prevention and scaling up for increased access to prevention of vertical transmission services.
3. Prevention of HIV transmission from mother-to-child is between B+ and C-. Despite the priority given to this by the NAA and the MoH, the drop-out rate from the prevention of vertical transmission program among HIV-positive mothers is still very high, often because service providers are highly and overtly critical of them and their behaviour.

In addition to highlighting the debilitating impact of HIV-related stigma and discrimination, the high drop-out rate indicates poor follow-up strategies and mechanisms for both mothers and infants. One reason is that it is unclear who or what is responsible for follow-up among those involved: health centre staff, the prevention of vertical transmission secretariat, NCHADS, community health workers or NGOs. It is hoped that such problems will be addressed by the National Strategic Plan for Preventing Mother-to-Child Transmission of HIV 2008-2015, which aims to further scale up services and achieve the UNGASS goal of reducing the percentage of HIV-positive babies born to HIV- positive women by 50 percent by 2010.

4. Provision of care and support for HIV-positive mothers, their infants, partners and families (Prong 4) is faring better than others and can be given an A-. The early focus of the national response to HIV/AIDS was on treatment. Over the past two decades NCHADS has allocated significant human, financial and technical resources toward this goal. Most women in need of ART have access to it, but coverage to infants born to mothers living with HIV remains limited due to lack of follow-up.

8 A = highest availability, B = high availability, C = low availability, and D = lowest availability.

*“PMTCT is poor in Cambodia: poor in terms of quality, cooperation, collaboration, coverage of services and high maternal mortality.”*

UN agency representative  
in Cambodia

## CHALLENGES OF THE PREVENTION OF VERTICAL TRANSMISSION PROGRAM IN CAMBODIA

- There has been a relatively low level of utilization of ANC services (30 to 50 percent). The majority of births (78 percent) occur at home or outside medical facilities in which prevention of vertical transmission services are available<sup>9</sup>. As a result, the vast majority of women of childbearing age miss the opportunity to be tested for HIV. Among the reasons for such low levels are lack of transportation; financial barriers; social/cultural norms and practices; and lack of confidence or trust in health care providers, especially those connected with the government.
- There is little awareness about prevention of vertical transmission interventions among the general population, including health care workers. This is largely due to limited availability of information about vertical transmission and low levels of education among women in rural areas.
- Access to prevention of vertical transmission services is hindered by poor integration with broader health care services. As of September 2008, there were 154 prevention of vertical transmission sites nationwide. Only 50 of them are housed in health centres – where most women in rural Cambodia go for ANC services – and the total number of sites is just a fraction of the nearly 1,000 health centres across the country.
- Many health centres have weak infrastructure in terms of qualified, motivated and committed staff, particularly in regards to midwives. This is due to a limited pool of health workers, low salaries and incentives; inadequate medicine supplies, equipment and buildings; and poor technical guidance, supervision and management systems. Many health care personnel work for only a few hours each day at health facilities; the rest of the day they may be at other jobs because they need to supplement their income.
- Weak planning, forecasting, procurement, logistic and supply management systems result in frequent stock-outs of prevention of vertical transmission drugs, HIV test kits and ARV medicines.
- The National Technical Working Group for PMTCT (TWG-PMTCT) has limited representation from the NGO and private sectors. This has resulted in poor coordination and limited awareness about prevention of vertical transmission among many NGOs that provide health-related services.

9 National Strategic Plan for Preventing Mother-to-Child Transmission of HIV, 2008-2015.

A key overarching challenge is institutional. Most respondents said that the scale-up of the prevention of vertical transmission program is inhibited by weak collaboration and cooperation between two key national health programs, NMCHC and NCHADS. The coordination of joint activities at national and sub-national levels remains limited despite a joint statement and set of standard operating procedures co-signed by NMCHC and NCHADS and approved by the health minister.

The growing divide in influence and resources is cited as a main reason for the lack of collaboration. Even though both NCHADS and NMCHC are equal in authority, NCHADS has more capacity in terms of human, technical and financial resources because HIV/AIDS spending has almost tripled over the past decade, while spending on maternal and child health has remained static. As one respondent observed, “There cannot be very good collaboration between rich and poor....It is very difficult to convince the rich to be coordinated with the poor.”

Efforts have been initiated recently to improve the situation by developing better linkages between HIV-related health services and other health services. One pilot project begun in four districts in April 2008 reportedly has shown good results with higher coverage of HIV testing among pregnant women than the national average and improved follow-up services for those testing positive<sup>10</sup>.

### **LESSONS LEARNED FROM THE PREVENTION OF VERTICAL TRANSMISSION PROGRAM**

Despite its many limitations, the prevention of vertical transmission program has played a vital role in increasing pregnant women’s utilization of antenatal care (ANC) and other services. Many respondents said that prevention of vertical transmission services will contribute significantly to a reduction in maternal and infant mortality and thus boost progress toward reaching several of the UN’s Millennium Development Goals (MDGs), notably goals 4, 5 and 6. Moreover, the prevention of vertical transmission program has helped boost HIV awareness among men, an increased number of whom are now directly engaged in ANC services with their wives, partners and family members. Many husbands of pregnant women who receive HIV tests are also seeking tests.

Other lessons learned from the ongoing scale-up of prevention of vertical transmission in Cambodia, as identified by country teams and respondents:

- Greater integration of prevention of vertical transmission services with maternal and child health services is needed to improve the

<sup>10</sup> Funds from the Global Fund’s Round 7 grant are supporting this pilot project, called “Linked Responses”, which is being implemented by NCHADS. Current plans are to scale up the project if the country’s Round 9 application is approved.

delivery of effective programs to prevent HIV infection in infants and young children.

- Effective scale-up of the prevention of vertical transmission program can only be achieved by providing more adequate infrastructure, increased training and resources for staff, and more reliable supply systems. It is difficult for public health systems characterized by low motivation and weak infrastructure to provide ANC and ART services to either women or infants.
- Most prevention of vertical transmission activities, including training and supervision, are initiated and conducted at the central level in Phnom Penh, Cambodia's capital. Such excessive centralization limits the technical capacity of management teams at the provincial and operational district levels to adequately implement services at the local level.
- A prevention of vertical transmission program is more likely to be effective in the long term if it implement pilot projects before scaling up national interventions. In Cambodia, the program was pilot-tested in three provinces before being expanded nationwide.
- A prevention of vertical transmission program should include partnerships with local policymakers, researchers, physicians, communities, NGOs and the private sector to increase awareness and support for project activities. For example, community norms, ideas, and support for a particular program or activity can influence a woman's decision to test for HIV. Unfortunately, such partnerships are far too few in number in Cambodia.
- The effective provision of rapid HIV testing, which is available at all prevention of vertical transmission sites in Cambodia, requires strong collaboration among ART, prevention of vertical transmission and laboratory staff. However, such collaboration is often lacking at sites in Cambodia, which means that some clients are not notified of their rapid test results on the same day they take the test.

### **3. HIV TESTING: ACCESS AND OTHER ISSUES**

A total of 212 VCT sites were operating in Cambodia as of December 2008; of those, 154 offered prevention of vertical transmission services. Provider-initiated HIV testing and counselling (PITC) was implemented in 2006 within various medical settings including prevention of vertical transmission, STI and tuberculosis clinics. This has increased HIV testing uptake and helped ensure appropriate referral to other health services. PITC implementation has also been beneficial for the prevention of vertical transmission program.

In 2008, according to government records, a total of 97,796 pregnant women obtained ANC services at government ANC clinics that offer prevention of vertical transmission services. Of those individuals, 67,973 (69.5 percent) were tested for HIV, and 15,529 (22.8 percent) of their

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husbands/partners were also tested. Of the 63,655 women who received the results of their HIV test, 383 (0.6 percent) were HIV-positive and subsequently referred to prevention of vertical transmission services; similar referrals were also made for an additional 363 pregnant women already known to be HIV-positive. More than 90 percent of these HIV-positive pregnant women reportedly received some prevention of vertical transmission prophylaxis. (It is important to note that the current VCT operating procedure and database management system only requires the classification of client by sex and not by pregnancy status.)

One major factor that prevents some women from accepting testing is the need to seek their partner's consent. If and when they do get tested, however, they may face some obstacles to adequate service provision. The overall quality of prevention of vertical transmission services is improving, but significant problems remain. Often, for example, prevention of vertical transmission specialists are able to devote only a few minutes to pre-test counselling for each client because of high demand and the fact that the specialists usually have additional responsibilities at their health centres. Confidentiality of test results is also not always guaranteed or ensured for women and their children.

According to several PLHIV respondents, some health care providers criticize HIV-positive mothers for becoming pregnant. Health care workers with insufficient training on prevention of vertical transmission often persuade HIV-positive women to abort their babies by telling them that they will die if they do not take that step. Given such pressure, it is not surprising that some HIV-positive mothers choose not to deliver at health care facilities.

#### **4. INFANT FEEDING GUIDELINES AND TRENDS**

Breast-feeding is considered normal in Cambodia and the National Policy on Infant and Young Child Feeding Practices (from 2002) recommends exclusive breast-feeding for up to six months after birth. The 2005 Cambodian Demographic and Health Survey reported that 60 percent of children younger than six months were exclusively breast-fed and that nearly half (46 percent) of mothers breast-feed their children until they are at least 2 years old.

The infant feeding guidelines in the national policy on prevention of vertical transmission (from 2005) focus primarily on informed decision-making. They state that HIV-positive mothers should be provided with as much information as possible about the risks and benefits of various feeding options. Health care providers are urged to support mothers who choose to breast-feed and they are directed to recommend formula feeding only when replacement feeding is acceptable, feasible, affordable, sustainable and safe (AFASS).

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Research findings indicate that such guidelines are not always followed in practice, however, by all stakeholders involved. Many public-sector and civil society personnel reportedly are biased in favour of the formula feeding option. An NMCHC representative said that NGOs in particular “interpret AFASS as simply asking HIV-positive mothers the question, ‘Do you accept formula feeding?’ with the understanding that the answer will always be yes”. As it stands now, nearly all (95 percent) of HIV-positive mothers in Phnom Penh, the capital and largest city, formula feed their babies up to six months after birth; the comparable rate in rural areas is far lower, at 45 percent.

Some NGOs and government facilities provide formula free of charge, but in most cases clients and their families must purchase it on their own. As a result, many women have no option other than breast-feeding, even when the child is older than six months.

Reports from across the country indicate that regardless of whether HIV-positive mothers breast-feed, follow-up with assistance and support for infant feeding practices is limited.

## 5. IMPACT OF VIOLENCE AND STIGMA

HIV-related stigma, domestic violence and lack of male involvement in antenatal care continue to discourage many women from accessing prevention of vertical transmission services in Cambodia. A 30-year-old participant of a focus group discussion at a health centre in Takeo province said that pregnant women often do not want to disclose their status to partners and families because they fear rejection, isolation and being forced out of their homes.

More effective prevention of HIV transmission among women is also hindered by cultural norms that leave them vulnerable to physical and sexual violence, often at the hands of their husbands<sup>11</sup>. Two respondents observed that such violence is often even greater (due to self-stigma) when the male partner is HIV-positive.

Another issue affecting pregnant women in general is the high rate of violence against women in Cambodia. According to one human rights NGO, more than 1,000 cases of violence against women and children were reported in 2008—a number that is almost certainly far lower than reality given the fact that the majority of such instances are not reported or are classified otherwise. At least one fifth of Cambodian women are thought to experience domestic violence every year. Addressing this problem is complicated by cultural and social norms that at the very least excuse such abuse. Recent studies indicate that more than half of Cambodian

*“I hope that PMTCT will  
be scaled up for the good  
health of mother and child.”*

HIV-positive woman

<sup>11</sup> Such violence and abuse was documented extensively in a 2005 publication from GTZ, “Gender-based violence and HIV/AIDS in Cambodia 2005”.

women justify a husband's violence against his wife for one reason or another, although young, urban, and educated women are less likely to consider domestic violence to be acceptable in any circumstance.

## 6. ASSESSING THE WORK OF GLOBAL AGENCIES

The prevention of vertical transmission program has received a high level of attention and support from many donors over the years, including bilateral agencies (such as DFID); UN agencies (including UNAIDS, UNFPA and UNICEF); and multilateral entities (including the Global Fund and WHO).

In 2007, the Cambodia PMTCT Program Joint Review was conducted with the financial support of UNICEF, the Clinton Foundation and the US Centers for Disease Control and Prevention (CDC). Technical advice for this process was provided by international consultants from UNICEF, WHO, CDC and the World Bank.

However, the disbursement of funds, particularly those provided through Global Fund grants, has been slow, a situation that has caused substantial delays in the expansion of services. Most of the donor money is channelled to only one institution (NCHADS), thereby leaving only a limited amount for the more appropriate institution, the National Maternal and Child Health Centre (NMCHC).

## RECOMMENDATIONS

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1. *Integration of services:* UNAIDS and the NAA should increase their resource-mobilization efforts and donor agencies should provide greater financial support for scale-up and integration of prevention of vertical transmission services in all health care facilities.
  2. *Policies and guidelines:* The MoH should revise guidelines to make the private sector more inclusive in comprehensive service delivery for prevention of vertical transmission. The new guidelines should allow services to be provided directly by health care facilities in the private sector, including all hospitals and clinics. The private sector should also be permitted (and should even be encouraged) to submit proposals to the Global Fund through the Country Coordinating Mechanism.
  3. *Coordination and management:* Civil society and private-sector representation in the national technical working group for prevention of vertical transmission (TWG-PMTCT) should be increased. This would help improve coordination among NCHADS, NMCHC, NAA, NGOs and the private sector and, ultimately, increase access to adequate services. The role and responsibilities of different representatives also should be made clear and specific in the TWG-PMTCT's terms of reference.
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4. *Financial support for women:* Pregnant women, particularly those from poor and marginalized communities, should be given financial and in-kind incentives by government agencies and/or donors to seek out and complete all stages of ANC, VCT and other prevention of vertical transmission services. Such incentives might include food and nutritional support and stipends for transportation to and from health care facilities.
  5. *Supply:* Government agencies such as NCHADS, NMCH, and the MoH's Central Medical Store, which are responsible for procurement, supply chain and logistics management systems in Cambodia, should strengthen their efforts to ensure consistent and regular availability of HIV test kits and ARVs for use in prevention of vertical transmission services.
  6. *Information-sharing and awareness:* NMCHC should develop and maintain a website that provides a centralized source of information and resources regarding prevention of vertical transmission, ANC and infant feeding. The website can help raise awareness about prevention of vertical transmission in general, especially among health care workers, program managers and policymakers.
  7. *Quality of services:* The MoH, the Ministry of Finance and/or donor agencies should identify ways to increase salaries and incentives of personnel providing prevention of vertical transmission services. Two important goals would be to have health care facilities open 24 hours a day, with at least one midwife present all the time.
  8. *Human rights:* Prevention of vertical transmission training should be provided to all health services providers and NGO implementers – not just to prevention of vertical transmission personnel. Such training would increase their understanding of prevention of vertical transmission and key human rights issues related to HIV, including confidentiality, non-discrimination and the importance of protecting a women's right to informed consent.
  9. *Community health systems:* Policymakers with the national prevention of vertical transmission program should increase linkages with all health-oriented service providers at the community level, including those operated by NGOs and the private sector as well as unaffiliated traditional birth attendants and community health workers. A full range of community members should also be involved in program planning and implementation to help reduce stigma and discrimination and to improve community awareness of HIV and prevention of vertical transmission services beyond MCH settings.
  10. *Breast-feeding:* HIV-positive mothers should receive appropriate information and counselling regarding the risks and benefits of various feeding options so they can make informed decisions. NMCHC should disseminate the national policy for infant feeding in the HIV context through its website, workshops and meetings to increase understanding at all levels of prevention of vertical transmission
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services and partners, including NGOs. NMCHC and NCHADS should establish a mechanism to follow up with HIV-exposed children to monitor appropriate infant feeding practices and their impact, and to offer appropriate counselling and advice to HIV-positive mothers during all facility visits.

11. *Male partner involvement:* The two national programs (NCHADS and NMCHC) should develop strategies to encourage male partners of pregnant women to be tested for HIV and engage more fully in prevention of vertical transmission services as part of a broader effort to involve the entire family in HIV treatment and care. Such strategies might include specifically urging male partners to accompany pregnant women to at least one ANC visit, sending written invitations to partners, and having community workers conduct home visits. Outreach activities to reach men who are at high risk, such as IDUs, male sex workers, and MSM, should be developed.
  12. *Counselling:* ANC procedures should be reorganized to provide pre-test information to groups of pregnant women (rather than individually). A group pre-test session would help to reduce the burden on providers and allow more time for the individual post-test counselling session. Pre-test counselling should explicitly address stigmatization of HIV-positive women and the potential for negative reactions to lead to violence. Such counselling should also provide tips to pregnant women on ways to persuade their partners to be tested for HIV, engage more fully in ANC activities, and consider behaviour-change counselling if appropriate.
  13. *Peer education:* All pregnant women should be encouraged to become peer educators. Requests could be made by health care providers during counselling sessions.
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# Moldova

**General coordination:** *Liudmila Untura, Childhood for Everyone*

**Interviews:** *Igor Chilcevcii, League of PLWHA in Moldova Republic; Igor Moiseev, Credinta; Natali Mordari, Childhood for Everyone; Vladlena Semeniuc, League of PLWHA in Moldova Republic*

**Report author:** *Liudmila Untura, Childhood for Everyone*

## KEY POINTS

1. A majority of HIV-infected women interviewed for the report said that the quality of pre- and post-testing counselling is very poor.
2. Knowledge about prevention of vertical transmission in general was relatively limited among focus group participants, including the importance of adherence to ART regimens and awareness of the risks of mixed feeding.
3. The barriers to deciding on the best infant feeding option for many mothers include stigma and discrimination; family pressure; and limited financial resources to purchase replacement feeding beyond the first year during which formula is provided free.
4. A recent survey of families with PLWHA found that half had faced HIV-related discrimination at least once, mostly in health care facilities.

## RESEARCH PROCESS AND METHODOLOGY

Research for this country report was conducted from November 2008 through mid-January 2009. It consisted of 14 interviews with government representatives, multilateral agencies, service providers, activists and women living with HIV. Respondents included staff from the MoH, including the agency's Healthcare Monitoring and Management Department and Scientific Research Institute on Mother and Child Health Protection; the Ministry of Social Welfare, Family and Child; the Human Rights Institute in Moldova; NGOs engaged in prevention of vertical transmission service delivery; and global agencies (including the Global Fund, UNAIDS, UNICEF and WHO). Also interviewed were the coordinator of the national prevention of vertical transmission program, the head of a local health facility unit providing care for HIV-positive women, and two gynaecologists from local health care facilities.

Researchers also conducted four focus groups with a total of 57 participants. Three of the focus groups comprised only HIV-positive women (a total of 42), some of whom were pregnant at the time. The participants came from both urban and rural settings across Moldova, including Belti, Glodeani, Falesti, Briceani and Ribnita in the north; Comrat and Chadir-Lunga in the south; Telenesti, Nisporeni and Traganesti in the west; and Benderi and Kausani in the east. The fourth focus group consisted of 15 women from the general population – i.e., women who were HIV-negative or otherwise did not know their HIV status.

## 1. BACKGROUND INFORMATION

Responding to the HIV/AIDS epidemic has been a priority of the Moldovan government in recent years. An interim evaluation of the national HIV/AIDS program 2006-2010 and national reports show that the situation has improved over the past few years. For example, ART is available free of charge to all who need it; all health services are available for free for pregnant HIV-infected women; and all maternity hospitals offer rapid HIV testing services and ARV prophylaxis for both pregnant women and newborns.

However, the development and sustainability of effective responses to HIV are threatened by lack of funding and resource-limited health care and welfare systems. One notable trend has been a growing feminization of the epidemic, a situation that has exposed significant limitations in prevention of vertical transmission service delivery.

## EPIDEMIOLOGICAL AND HIV TREATMENT SITUATION

According to the National AIDS Centre, a total of 4,926 HIV cases had been officially registered in Moldova by the end of 2008. The annual number of new cases has increased in recent years, from 618 in 2006 to 795 in 2008.

The epidemic has long been concentrated among IDUs, but their share of infections has decreased over the past several years while the percentage of infections attributed to heterosexual sex has increased. The majority – 62 percent – of new cases occur among individuals aged 20 to 34. In 2008, women comprised about 44 percent of all new registered HIV cases.

ART is available free of charge for all who have need for it in Moldova, and both first- and second-line regimens are available. As of the beginning of 2009, a total of 585 people were on ART, including 29 children. A total of 102 HIV-positive pregnant women received ARV prophylaxis in 2008. Four cases of vertical transmission were recorded that year.

## 2. STATUS OF SERVICE DELIVERY AMONG AND FOR WOMEN

Policies and guidelines for prevention of vertical transmission services are defined in the government's national HIV program. They include the following:

- *Primary prevention of HIV infection among women and girls.* Numerous HIV awareness campaigns have been conducted in Moldova. Most have been targeted at young people, IDUs, MSM and other key at-risk populations, but the government in collaboration with other partners has also created a special “Guidelines on PMTCT Issues”. These guidelines, which discuss key messages and priorities in regards to prevention of vertical transmission, have been distributed to health care facilities across the country.
  - *Prevention of unintended pregnancies among HIV-positive women.* When women access VCT services, they receive pre- and post-test counselling on a range of different HIV-related issues, including prevention of vertical transmission and various risks associated with becoming pregnant if HIV-infected. Counselling guidelines emphasize the importance of using condoms to avoid unintended pregnancies as well as reduce HIV transmission risk; also, they provide guidance on how HIV-positive women might manage intended pregnancies.
  - *Prevention of HIV transmission from mother-to-child.* Almost all women receive HIV testing (including counselling) during pregnancy. Free ARV prophylaxis is available to all HIV-positive women in antepartum and postpartum periods as well as during delivery. Newborn infants are placed immediately under medical observation, which includes HIV testing (assuming parental consent) as soon as accurate results are likely to be available. National protocols state that HIV-positive
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women should breast-feed their infants exclusively during the first six months only if formula is not available or if the woman does not want to use formula for a personal reason. The protocols also strongly recommend that mothers switch from breast-feeding to formula six months after birth if formula is available. Women are informed about the risks of breast-feeding and mixed-feeding, and infant formula is offered and made available free of charge for one year for all children born to HIV-positive mothers.

According to the most recent UNGASS report (2008), nearly 85 percent of pregnant HIV-positive women received ARV prophylaxis in 2007. Two different three-drug combinations are currently offered and available<sup>12</sup>. ARV prophylaxis for prevention of vertical transmission can be provided to women in only two cities in the country, Chisinau and Tiraspol. Newborns, however, can get ARVs at maternity hospitals across the country.

#### **PROVISION OF CARE AND SUPPORT FOR HIV-POSITIVE MOTHERS, THEIR INFANTS, PARTNERS AND FAMILIES**

This component of prevention of vertical transmission is provided partly by NGOs under the patronage of “The League of PLWH in Moldova Republic” (also known as “League of PLWH”). Services provided include peer-to-peer support, group counselling and telephone counselling. Public health facilities, meanwhile, provide only clinical observation of HIV-positive women and their children. Medical care for all pregnant women is provided free of charge in the public sector.

The government also provides financial support (“hardship allowance”) on general grounds to those in need. It does not, however, automatically provide psychological and social support to HIV-positive women and their children, a service that would be especially useful in helping them adhere to treatment regimens.

#### **BARRIERS TO COMPREHENSIVE SERVICE DELIVERY AND LESSONS LEARNED**

For the most part, the government – with crucial financial support from the Global Fund – has done a decent job in developing and implementing prevention of vertical transmission services that reach the majority of women in need. However, uptake of these services has lagged for a number of reasons. Existing support systems fail to motivate patients to ask for the medical services and assistance they have a right to access. Residents of rural areas encounter tremendous difficulties in obtaining essential medical care in a timely and convenient manner. Chronic shortfalls in human resources and governmental budget financing for health care in general also negatively affect service delivery.

<sup>12</sup> The three-drug combinations available include i) nevirapine+AZT+3TC and ii) Kaletra (lopinavir/ritonavir)+AZT+3TC.

*“The director of the local kindergarten asked me to remove my children – who happen to be HIV-negative, by the way – and never bring them back. She is not a bad person, but parents of other children demanded that my kids be removed. Our town is very small. Everybody knows everything about each other. Rumours about my diagnosis have spread all over the town... I don’t understand why the nurse from our health care district told my neighbours about my status.”*

**Svetlana, 28, an HIV-positive woman who participated in a focus group discussion in Beltsy in December 2008**

Developments have also been relatively limited from a social perspective. Gender-oriented approaches have yet to be integrated into all parts of the national HIV program. Patriarchal traditions and stereotypes continue to influence expectations regarding women’s role in society, such as the assumption that they have primary responsibility for child-rearing and family relations.

### **FEEDBACK FROM FOCUS GROUPS**

The following challenges in regard to prevention of vertical transmission service delivery in Moldova stem from information and observations obtained during focus group discussions:

- The overwhelming majority of focus group participants had incomplete or distorted knowledge about HIV transmission modes and risks. The lack of awareness was most significant among participants from the “general” population (i.e., not HIV-positive). Many of them thought HIV could be transmitted through casual contact and bloodsucking insects.
- Even HIV-positive focus group participants, however, knew relatively little about prevention of vertical transmission in general. The importance of adherence to ART regimens was poorly understood, and even pregnant HIV-positive women had limited knowledge of the risks of mixed feeding.
- A majority of HIV-positive women from rural areas said they received adequate information about ARV prophylaxis only after visiting the facility in Chisinau where specialized care is provided for pregnant women living with HIV. Most were unaware that support and services in regards to prevention of unintended pregnancies were available.
- A majority of HIV-positive women said that the quality of pre- and post-testing counselling is very poor. In some cases this appears to have had disastrous consequences. One woman said she did not receive any counselling at all, was not aware that she had been tested for HIV by health care providers (most likely her gynaecologist), and was not told she was HIV-positive until after she gave birth. Her child was later diagnosed with HIV and is now on ART.
  - A majority of focus group participants wished that the quality and scope of available medical services could be improved. Most said, for example, that they thought follow-up examinations should be available free of charge; they also wanted free dental health service.
  - All focus group participants would like to receive extra nutritional support for their children and themselves as well as extra hardship allowance from the government on the grounds of their HIV status.

## LESSONS LEARNED

The following are among the lessons learned in regards to prevention of vertical transmission service delivery during interviews and focus group discussions:

- Greater collaboration should be initiated among all stakeholders involved in HIV prevention and treatment efforts in Moldova, including the national MoH and its relevant departments, local authorities, civil society, and multilateral and bilateral agencies and donors.
- Prevention activities must be based on facts that accurately reflect the situation. It is therefore necessary to create and develop a comprehensive database in which HIV data and information are up-to-date and widely available.
- Governmental structures should work more closely with experienced and trusted NGOs, such as organizations of HIV-positive individuals, to develop and roll out improved psychosocial support mechanisms that are beneficial to HIV-positive women and their children.
- Some women (HIV-positive or not) do not have reliable access to adequate and consistent health care even if they are pregnant. The main obstacle has been that Moldova is a relatively poor country and many insurance schemes are unable to provide comprehensive coverage. The government has, however, sought to fill the gap by guaranteeing free health care to pregnant women starting at the 14th week of pregnancy.

## 3. HIV TESTING: ACCESS AND OTHER ISSUES

A total of 32 VCT sites are currently operating in the country, and the government plans to open at least 20 more by the end of 2010. Respondents indicated that the sites meet international standards and personnel are well-trained. In addition to HIV testing (ELISA and Western Blot, depending on location), the sites offer tests for hepatitis B and C. (Rapid testing is currently not available at VCT sites, but the government plans to provide them at such facilities by the end of 2010. Currently, rapid tests are only available at maternity hospitals.) PCR tests are available for children born to HIV-positive mothers, as per new WHO guidelines adapted for Moldova. All tests are available free of charge.

As per a national law, HIV tests are mandatory for pregnant women who utilize health care facilities in Moldova—although women who refuse to be tested are not prosecuted. Women who register at facilities when pregnant are normally tested twice, once when they first register and again during the third trimester. According to officials at the National AIDS Centre, about 97 percent of pregnant women do in fact get registered and, thus, are tested for HIV during pregnancy (about 30,000 women per year in total). Taking rapid testing into account (which is

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*“I feel sorry for HIV-infected girls, but I’m an [infectious-disease specialist] and I don’t have time to talk to them about pregnancy. I’m not a psychologist who can help dry their tears and tell them how to live now... but someone needs to do that!”*

**Infectious-disease specialist at a Chisinau clinic, interviewed in December 2008**

currently available only in maternity hospitals), this number is very close to 100 percent, which makes prevention of vertical transmission planning and implementation easier in Moldova.

All aspects of HIV testing, including results, are confidential as per a 2007 law. Even so, HIV-positive people do not always have control over information about their status. For example, the 2007 law also mandates that information about patients’ HIV status be sent to his or her specific health care service provider, who has ultimate responsibility for treatment. The law also permits health care providers to i) inform parents of minors without the young person’s consent, and ii) divulge HIV status information to the spouse or partner of an HIV-positive person if a “risk” of HIV transmission is perceived by the provider.

The law does, however, forbid medical personnel from discussing individuals’ HIV status outside such specific instances. Several HIV-positive respondents said that this provision is commonly violated at different points in the system. One focus group participant said the following: “When I was at the hospital for TB treatment, all the staff members and even other patients knew about my HIV diagnosis.”

#### **4. INFANT FEEDING GUIDELINES AND TRENDS**

National protocols state that HIV-positive women should breast-feed their infants exclusively during the first six months only if formula is not available or if the woman does not want to use formula for a personal reason. The protocols also strongly recommend that mothers switch from breast-feeding to formula six months after birth if formula is available. Women are informed about the risks of breast-feeding and mixed feeding, and infant formula is offered and made available free of charge for one year for all children born to HIV-positive mothers.

Global Fund support helps ensure that formula is available free of charge for all HIV-positive mothers who want or need to use it during the first year of a child’s life. Counselling on complementary feeding is available during antepartum and postpartum periods in health care facilities, family planning centres and reproductive health centres. The counselling covers such topics as the preparation of infant formula, dosage and guided practice. Counselling and support are also provided by family doctors and paediatricians, who often visit mothers and their infants at home.

Special medical support is also available for children born to HIV-positive mothers. Under existing policies, they are guaranteed medical check-ups by the specialist at the facility in Chisinau at least once every three months. The policies also strongly recommend that the children be examined regularly by other specialists if necessary, including a neurologist and orthopaedist. Caseworkers visit children born to HIV-positive mothers at least once every 10 days during the first three months



after birth, and then once a month after the third month. All children regardless of type of feeding are tested for HIV at 2, 4 and 18 months.

An MoH executive order (from June 2007) states that all children born to HIV-positive mothers should be provided with formula for the first year of their life. Medical personnel are trained to provide counselling on infant feeding. In reality, though, formula feeding is not always AFASS for HIV-positive mothers in Moldova, a situation that prompts some to choose not to follow the national policies. According to some focus group participants and beneficiaries of NGO services, many mothers continue breast-feeding after six months for various reasons, including financial hardship. (For example, some women – especially those who live in rural areas far from facilities – are unable to afford the cost of transportation on a regular basis to obtain formula, even though it is provided free of charge.)

Additional barriers to AFASS replacement feeding for many mothers include i) stigma and discrimination based on that feeding method, ii) violence against women, iii) family pressure against replacement feeding; iv) inadequate social support on the part of the government; and v) lack of financial ability to acquire extra formula and nutritious food, especially after the first year of life (when the formula is not provided for free any more). Such obstacles often reduce the quality of children's lives.

*“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 years old, an HIV-positive participant in a focus group held in Chisinau in November 2008**

The government recognizes such factors and obstacles and has taken steps to address them. In addition to targeted efforts to reduce poverty across Moldova, it has initiated an effort to increase women's social status and reduce discrimination against them. For example, governmental commissions have been created at the national level to help identify and coordinate activities of the Department of Equal Possibilities and Family Policy in the Ministry of Social Protection, Family and Child. Funds are to be made available through the Global Fund Round 8 project, which was approved in November 2008, to seek improvement in the quality of lives of PLWHA. Specific plans in the successful Global Fund application call for reducing HIV-related stigma and discrimination and providing support (including nutrition and clothes) to children infected with and affected by HIV.

## **5. IMPACT OF VIOLENCE AND STIGMA**

HIV-related stigma and discrimination remain extensive in Moldova despite the government's commitment to respond appropriately to the epidemic. In practice there are few repercussions for discriminatory actions and no compensation is provided even for those who can prove they experienced stigma and discrimination.

The general feedback from respondents is that informational campaigns aimed at reducing HIV-related stigma have not been effective. Such observations reinforce the findings of a survey about and among people

affected by HIV that was conducted by the National Centre of Public Health Management in 2008. The survey consisted of interviews with 576 families of PLWHA between the ages of 18 and 50. More than three quarters (76.5 percent) of survey respondents said they found it difficult to talk about their HIV status, and the majority of those said stigma was the main reason. Perhaps the most shocking result was the high level of inappropriate and illegal behaviour on the part of health care providers. Half of those surveyed said they had faced HIV-related discrimination at least once, mostly in health care facilities. Forty-four percent of study participants said that confidentiality had been breached when an HIV diagnosis was inappropriately revealed; in nearly half of those cases, doctors were identified as the source of disclosure.

Violence against women in Moldova is relatively common, a situation that further undermines the ability and inclination of HIV-positive women to disclose their status and seek out appropriate treatment and care. For example, according to an article published in 2007 in *Entre Nous, the European Magazine for Sexual and Reproductive Health*, about one third of all Moldovan women under 30 years of age had been the victim of violence after turning 15. About the same percentage of women who had ever been married said that they had experienced psychological or sexual violence from their present or ex-husband.

## 6. ASSESSING THE WORK OF GLOBAL AGENCIES

Global agencies have long been involved in Moldova's HIV/AIDS response. Their involvement became especially significant in 1996, with the establishment of a special UN coordinating body to assist the government in addressing the epidemic. In addition to key government agencies, the body includes representatives from the Global Fund, UNAIDS, UNDP, UNFPA, UNICEF, WHO and the World Bank. The body helps develop and implement effective strategies to fight the epidemic and, among other things, advocates for multisectoral approaches in regards to the implementation of activities related to HIV prevention and treatment, including HIV-positive women and children born to HIV-positive mothers.

Most government officials and civil society advocates agree that the overall impact of global agencies on HIV-related treatment, care and support, including in regards to prevention of vertical transmission, has been positive. Several agencies deserve special recognition for the type and scope of support they have provided. The Global Fund has played a vital role by approving more than \$25 million in grants to date for Moldova's HIV/AIDS programs, including those related to prevention of vertical transmission. UNICEF, meanwhile, has helped manage prevention of vertical transmission services; its financial support helped renovate a special facility for HIV-positive women and their children and underwrote a survey on the impact of HIV on children.

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It is worth noting, however, that the majority of individuals interviewed for this study had no knowledge of the global agencies' involvement. Several government officials were unable to describe or explain the agencies' activities, and nearly all focus group participants had never heard anything about the organizations or their engagement in the HIV/AIDS response in Moldova.

## 7. RECOMMENDATIONS

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Stakeholders should take the following actions to improve prevention of vertical transmission services for women and children in Moldova:

### NATIONAL GOVERNMENT:

- Increase financing of prevention of vertical transmission programs at all levels through the national budget.
- Strengthen interaction between civil society and the government. One step would be to increase the number of PLWHA in the Global Fund CCM to three and ensure gender balance.

### LOCAL AND NATIONAL AUTHORITIES:

- Develop and roll out an informational campaign designed to increase awareness of HIV and STIs, including effective prevention strategies. This campaign should be undertaken in collaboration with NGOs and should reach all administrative territories and rural areas and should emphasize the importance and availability of VCT services.

### MINISTRY OF HEALTH:

- Create a dedicated unit within the MoH to focus on HIV/AIDS. This unit would be responsible for coordinating all HIV-related care, treatment support services at all levels across the country. The current system is fragmented, with different entities within the general public health system having responsibility for different elements of HIV service delivery. For example, prevention of vertical transmission services should be integrated more fully into an overall spectrum of HIV-related care.
  - Develop and implement a program to monitor and follow patients throughout all stages of HIV care, from the moment of diagnosis to ART provision to managing OIs and side effects.
  - Develop and implement a program improving access to medical services not related to ARVs and reproductive health for women and children. This would mean, for example, that HIV-positive women could receive free medical care for any and all conditions, regardless of whether they have insurance.
  - Hire an HIV paediatrician to work at the special hospital unit for HIV-positive children. Currently children are treated by doctors specializing in care for adults.
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- Ensure that VCT services for HIV are available in all health care centres and family planning clinics in the country.
- Develop and publish guidelines that expand awareness of VCT services.
- Create a national centre for HIV/AIDS specialists' education at which prevention of vertical transmission specialists are trained. Eligibility should extend to both governmental and NGO employees.
- Develop the program that helps motivate women to seek out and request prevention of vertical transmission services and medical care.

#### **MINISTRY OF EDUCATION:**

- Develop and implement a dedicated program to provide key health and sexuality information in educational institutions. This program should include comprehensive information about all aspects of HIV and prevention of vertical transmission. Similar programs could be established to reach young people outside of school environments, including outreach and training on peer-to-peer education. NGOs working with and for PLWHA should be included in all of these efforts because they have significant experience.
- Develop and distribute HIV and prevention of vertical transmission education materials for pupils and students, teachers and parents.

#### **MINISTRY OF SOCIAL PROTECTION, FAMILY AND CHILD:**

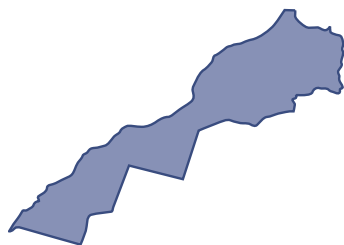
- Develop and implement a program that would ensure social protection of HIV-positive women and children. More specifically, this would include financial support for those utilizing prevention of vertical transmission services. Funds could be used to reimburse women for transportation costs to and from clinics and to purchase nutritious food for themselves and their children, for example. Another priority would be to provide special welfare payments for HIV-positive children so their caregivers can better support them.

#### **MINISTRY OF JUSTICE:**

- Revise laws and by-laws on HIV/AIDS in order to bring them to conformity with international standards on protection of rights of HIV-positive individuals. A key priority would be to revise the 2007 law on confidentiality so that individuals' HIV status cannot be divulged without their informed consent.

#### **MEDIA:**

- Create a series of advertisements for TV, radio and newspapers that focus on reducing HIV-related stigma and discrimination against women.
  - Initiate a wide-ranging campaign to raise the level of awareness about prevention of vertical transmission programs and services.
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# Morocco

By Othoman Mellouk, *Association de Lutte Contre le SIDA Marrakech*, and Nadia Rafif, CSAT<sup>13</sup> regional coordinator for MENA<sup>14</sup> region

## KEY POINTS

1. To date, no brochures, posters or information booklets specifically discussing prevention of vertical transmission have been prepared by either the Ministry of Health or any NGOs, and no NGOs are involved in programs promoting or offering VCT to women during pregnancy.
2. Access to antenatal services remains insufficient: just 68 percent of Moroccan women have access to at least one antenatal exam during pregnancy, and only 63 percent of births are assisted by healthcare professionals.
3. Breast-feeding by HIV-positive mothers is contraindicated by the Ministry of Health, however, more than 40 percent of rural-dwellers do not have access to safe drinking water sources, and formula is available free of charge in only three cities.
4. A lack of coordination among international agencies working in Morocco limits their overall effectiveness. Currently, for example, both UNFPA and UNIFEM are focusing on improving maternal and child health and promoting reproductive health for women and girls, but are not fully coordinated.

## RESEARCH PROCESS AND METHODOLOGY

Research for this report was conducted in two phases. The first phase (November and December 2008) consisted of collecting and reviewing recent documents and reports produced by government agencies and NGOs. The second phase, in January 2009, included interviews with a total of 11 stakeholders: representatives from UNAIDS, the National AIDS Program, the Global Fund management unit, and civil society groups (including those focusing specifically on HIV and human rights); health-sector workers (including paediatricians, infectious-diseases specialists, and social workers); and consultants who have worked on prevention of vertical transmission issues for the MoH, UN agencies and civil society organizations. A focus group with five HIV-positive mothers was organized in Marrakech in January 2009.

## 1. BACKGROUND INFORMATION

An estimated 22,000 Moroccans were HIV-positive in 2008, which corresponds to a relatively low prevalence of just 0.1 percent. However, epidemiological data show signs of emerging concentrated epidemics among specific populations including female sex workers and IDUs.

HIV is also becoming more common among women in general. In 2008, they comprised 38 percent of all recorded AIDS cases<sup>15</sup>, up from 28 percent in 1995 and 19 percent in 1990. Marriage is no barrier to HIV infection: according to official sources, three quarters of women living with AIDS are currently married, divorced or widowed. Studies on STIs<sup>16</sup> indicate that it is mostly husbands' sexual behaviour that put Moroccan women and, subsequently, their infants at risk of HIV infection. Vertical transmission is responsible for about 3 percent of reported AIDS cases. Local and global demographic and epidemiological data indicate therefore that some 200 Moroccan infants contract HIV through vertical transmission each year.

Systems for care, treatment and support for people living with HIV are relatively well advanced, with antiretroviral drugs and treatment now available free of charge. So-called centres of excellence and referral centres have been established, and they are adequately trained and equipped to treat HIV. Since 1990 these centres have provided treatment

<sup>13</sup> Civil Society Action Team

<sup>14</sup> Middle East and North Africa

<sup>15</sup> The MoH provides data only on recorded AIDS cases, not cases of HIV infection. The ministry defines 'AIDS' as per standard WHO guidelines.

<sup>16</sup> Ryan CA, Zidouh A, Manart L et al., "Reproductive tract infections in primary health care, family planning and dermatovenereology clinics: Implications for syndromic management in Arab Muslim women." January 1998

for HIV-positive pregnant women to prevent vertical transmission. Prior to ARVs becoming widely available and free of charge to all in need, in 2003, treatment for pregnant women consisted first of zidovudine (AZT) monotherapy and then of dual therapy (AZT+3TC). In 1998, triple-combination therapy became available to HIV-positive pregnant women in need.

In terms of identifying PLWHA, over the past decade Morocco has undertaken extensive efforts to reach high-risk individuals with HIV/AIDS information, education and VCT services. Those efforts have not been successful in regards to pregnant women, however. According to the most recent UNGASS report, only 7.5 percent of HIV-positive pregnant women had access to prevention of vertical transmission services in 2007. In September 2008, there were 156 children in Morocco (0 to 14 years of age) followed in reference services for HIV infection. In 80 percent of cases, the HIV status of one or both of the parents was revealed only after the child's status was confirmed<sup>17</sup>. Such poor performance highlights the fact that prevention of vertical transmission remains a major weakness of the National AIDS Program.

## **2. STATUS OF SERVICE DELIVERY AMONG AND FOR WOMEN**

Policymakers recognize the shortcomings in availability of prevention of vertical transmission services and are trying to address the situation. With the support of UNAIDS and UNICEF, the MoH since 2006 has sought to assess vertical transmission in the country and develop recommendations for improved services. As a result, prevention of vertical transmission is one of the innovations of the new National AIDS Strategic Plan 2007-2011, and a pilot program has been initiated recently in the cities of Agadir, Marrakech and Casablanca<sup>18</sup>. The results of this pilot program will help determine whether, and how, prevention of vertical transmission services will be expanded throughout the country. The current prevention of vertical transmission strategy is much more limited in that it focuses primarily on services for women already known to be HIV-positive.

The MoH's pilot program was preceded by a much smaller one launched in 2006, in the city of Rabat. That pilot study, initiated by the University Hospital Ibn Sina and supported by the French quasi-governmental organization ESTHER<sup>19</sup>, was the first program in Morocco offering "comprehensive" prevention of vertical transmission services to pregnant

17 Évaluation rapide de la situation des enfants infectés ou affectés par le VIH/SIDA au Maroc, Marc Eric Gruenais, 2009 (Moh, UNAIDS, IRD, Soleil)

18 The program started in September 2008. Of the total of 916 pregnant women tested through December 2008, just two were diagnosed as HIV-positive. As of March 2009, it was unclear when the pilot program would end or when results, preliminary or otherwise, would be made available.

19 Ensemble pour une solidarité thérapeutique en réseau.

women. From October 2006 to June 2008, a total of 1,527 pregnant women enrolled in the program. Of them, five tested positive for HIV and received ARV prophylaxis. All five babies are HIV-negative.

To date, with the exception of the ESTHER-supported pilot study in Rabat and the pilot program recently launched by the MoH, there are no other programs offering a comprehensive package of prevention of vertical transmission for pregnant women in the country.

### **PRIMARY PREVENTION AMONG WOMEN AND GIRLS**

The MoH and various NGOs have taken the lead in raising general awareness about HIV through a growing number of HIV/AIDS education campaigns in recent years. These campaigns have taken several forms, including media campaigns and prevention programs in schools and at work places.

Campaigns specifically targeting women have been initiated. Some NGOs, such as ALCS<sup>20</sup>, have built alliances with women's organizations in order to provide information and testing services to their beneficiaries. AMSED<sup>21</sup>, a national development organization, works with a large network of community-based organizations (especially in rural areas) and has offered information about HIV in its programs. None of these interventions provides detailed information about prevention of vertical transmission, however; in most cases, the focus is on sexual transmission and condom use, with vertical transmission of HIV discussed only superficially<sup>22</sup>. To date, no brochures, posters or information booklets specifically discussing vertical transmission have been prepared by either the MoH or any NGOs. Moreover, no NGOs are involved in programs promoting or offering VCT to women during pregnancy.

### **PREVENTION OF UNINTENDED PREGNANCIES AMONG HIV-POSITIVE WOMEN**

There is a lack of data concerning reproductive choice and HIV in Morocco, with the exception of a small study undertaken in Casablanca in 1999<sup>23</sup>. According to one respondent<sup>24</sup>, all HIV-positive women followed in specialized care facilities that provide HIV treatment and care (two centres of excellence and seven referral centres) receive adequate

20 Association de Lutte Contre le SIDA ([www.alcsmaroc.ma](http://www.alcsmaroc.ma)).

21 Association Marocaine de Solidarité et de Développement.

22 Researchers for this report analyzed materials (brochures, posters, PowerPoint presentations, audiovisuals, etc.) used by NGOs working with women. None of these focus on all components of prevention of vertical transmission.

23 Chakib A, Laghzaoui Boukaidi M, Najib J et al. Grossesse et SIDA. A Propos de 9 Cas. La Tunisie Médicale, Vol. 79, N. 10 2001 ; 530-535. The study found that two of the nine HIV-positive pregnant women treated at the Maternity Service of the Teaching Hospital Ibn-Rushd from 1990 through 1999 said their pregnancies had not been planned. However, all women surveyed who knew their HIV status before pregnancy said they decided themselves to have babies after consulting with their doctor.

24 Dr. Hakima Himmich, president of ALCS (Association de Lutte Contre le SIDA) and head of the infectious disease department at Casablanca's University Hospital Ibn Rochd.

information about family planning from medical personnel and have access to contraceptive information and materials. (All HIV-positive women respondents for this case study confirmed having received such information.)

Abortion is illegal in Morocco, but HIV/AIDS is an indication for the therapeutic interruption of pregnancy if the woman desires it. This interruption is possible only after the mother is provided a thorough explanation as to the HIV transmission risks and the potential fetal toxicity of ARVs. After receiving such information, she can decide whether she wishes to interrupt her pregnancy or carry to term. Of the 23 pregnant HIV-positive women followed in the Casablanca centre of excellence in 2008, four chose to have an abortion.

*“I fell sick after the birth of my son. My child had TB. The doctor ended up advising me to have an HIV test. It was positive... During my pregnancy I was followed in a clinic, but I never heard about the possibility of taking an HIV test. I vaccinated my child and breast-fed him... he died at nine months. Today, I feel guilty.”*

**35-year-old HIV-positive woman**

#### **PREVENTION OF HIV TRANSMISSION FROM MOTHER-TO-CHILD**

Treatment and care of HIV infection in Morocco is provided at two centres of excellence and seven referral centres. ART and key diagnostic tests are provided free of charge to all in need, including pregnant women.

HIV/AIDS treatment and care protocols have recently been revised to meet WHO recommendations. The guidelines stipulate that all HIV-positive pregnant women be assessed upon first presentation at a centre to determine whether they need ART and other therapies such as cotrimoxazole prophylaxis. The usual ART regimen provided is AZT+3TC+Kaletra (lopinavir/ritonavir). That combination regimen is available immediately, if deemed necessary, or beginning at the 28th week of gestation if it is intended to serve as prophylaxis. The treatment protocols also specify when other ARVs may be more appropriate, such as when just one dose of nevirapine is given during birth to help reduce transmission risk to the newborn.

All newborn infants receive AZT within eight hours after birth and remain on treatment for four weeks. When there is high risk of vertical transmission (when women have high viral load), a single dose of nevirapine is given to the newborn within 72 hours of birth as well.

HIV-positive pregnant women are strongly encouraged to give birth in one of the nine specialized centres in the country. However, some women do not follow this advice and choose to deliver elsewhere, usually at their local maternity clinic, because of the stigma associated with the specialized centres.



## **BARRIERS TO COMPREHENSIVE SERVICE DELIVERY AND LESSONS LEARNED**

- For many years, different stakeholders were sceptical, mainly because of the very low HIV prevalence in Morocco, as to the cost effectiveness of a dedicated prevention of vertical transmission program. This points to a lack of documented best practices from low-prevalence countries regarding this issue. The strategy ultimately adopted was to treat known HIV-positive women and to continue raising awareness (including the promotion of VCT) among the general public. At the same time, several discussions and debates took place around the country to define the most appropriate future strategy to promote prevention of vertical transmission. This resulted in the MoH-organized pilot program now in place.
  - For the time being, it is considered neither practical nor reasonable from a cost point of view to recommend that all pregnant women in the country be tested for HIV. Previous STI studies indicate that it is difficult to identify women at risk of HIV infection in Morocco because it is the sexual behaviour of their husbands that often puts those women at risk. However, efforts have been made to determine the types of behaviours and circumstances that pose a risk of HIV infection for pregnant women in Morocco. Key factors include a history of multiple sexual partners or professional sex work, multiple diagnoses of STIs, and having male partners (including husbands) who work away from home for extended periods of time.
  - Although progress has been made during the last decade to reduce gender inequalities, 38 percent of Moroccan women are illiterate and therefore cannot obtain information about HIV from brochures, posters and the written media.
  - Access to antenatal services remains insufficient. Just 68 percent of Moroccan women have access to at least one antenatal exam during pregnancy, and only 63 percent of births are assisted by health care professionals.
  - Women seem to bear the burden of prevention of vertical transmission and the consequences of a possible positive HIV test by themselves. Husbands are rarely if ever involved. For example, they hardly ever accompany their wives to antenatal consultations and have limited awareness of anything related to vertical transmission.
  - There are relatively few sites in the country that offer dedicated HIV-related services, notably prevention of vertical transmission, to pregnant women. (At the moment, in fact, there are only four: the sites established in 2008 as part of the MoH's pilot program.) The most convenient option for the majority of pregnant women who wish to be tested is to use a VCT centre run by an NGO. However, they rarely utilize that option because they fear being identified as perhaps having HIV.
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*“For now, I do not think we should rush to generalize the practice of testing pregnant women all over the country. We must await the results of the pilot program and draw the necessary lessons. Personally, I do not think we’ll go toward a generalization but rather focus the program in the most affected areas with the highest prevalence rates.”*

**Dr. Kamal Alami, administrator of the UNAIDS program in Morocco**

### **3. HIV TESTING: ACCESS AND OTHER ISSUES**

#### **HIV TESTING POLICIES AND PROCEDURES**

Morocco has a good national policy on HIV testing under a legal framework contained in an MoH decree from 1989<sup>25</sup>. Testing is voluntary, anonymous (except diagnostic testing<sup>26</sup>) and free of charge. Informed consent is required. Only trained physicians are permitted to give HIV tests. Recently, though, with the launch of the prevention of vertical transmission pilot program, nurses are authorised to provide pre-test counselling—but only doctors are allowed to give patients their test results, whether negative or positive.

To date, testing in Morocco is offered primarily by NGOs<sup>27</sup> in close collaboration with the MoH, which provides the test kits (rapid tests and Western Blot confirmation tests) and other equipment for VCT centres. More than 40 VCT centres are currently run by NGOs across Morocco (including at least six mobile units operated out of vans), but several regions of the country still have no testing facilities. About 14,000 HIV tests were performed between July 2007 and December 2008. Nearly three quarters of all HIV tests in 2008 were performed at VCT sites and mobile vans operated by one NGO: ALCS.

#### **UPTAKE AND ACCESS TO TESTING AMONG WOMEN**

According to available data, women are relatively well represented at testing sites in urban areas. In 2008, for example, women comprised more than half (53.5 percent) of all people tested for HIV at ALCS-operated freestanding centres, the majority of which are located in urban areas. Women’s share is much lower in rural and remote areas.

However, all NGO testing sites reported few, if any, pregnant women coming for HIV tests. The majority of female clients are most at-risk women (notably, regular or occasional sex workers). Since few of them become (or remain) pregnant, testing this cohort does not play an important role in prevention of vertical transmission.

#### **HIV TESTING FOR PREGNANT WOMEN**

Because there have been no systematic efforts to educate pregnant women about the risk of vertical transmission and the benefits of VCT, the actual level of demand for VCT among pregnant women in Morocco is unknown. With the exception of the few prevention of vertical transmission programs currently in operation, HIV testing is not available in antenatal

<sup>25</sup> Ministry of Health Decree N° 1078/DT/217/SLMSTD (21/09/1989).

<sup>26</sup> Diagnostic testing is not technically anonymous because it takes place after the patient is already registered in a health care facility and has a medical record containing his or her name. However, health care providers are required to respect patients’ confidentiality.

<sup>27</sup> Association de Lutte Contre le SIDA (ALCS), Organisation Panafricaine de Lutte contre le SIDA (OPALS), Ligue Marocaine de Lutte contre les MST (LM-LMST) and smaller NGOs such as the Association de Lutte Contre les IST-SIDA (ALIS).

care facilities. Some physicians in the private health sector reportedly give HIV tests to their pregnant patients without informing them. In such cases, according to respondents, the physician will refer a woman to a centre of excellence if the test comes back positive—and she is only told that the test was administered, and the result, after registering at the centre. The ethics of this practice are questionable.

#### **TESTING IN PREVENTION OF VERTICAL TRANSMISSION PROGRAMS**

In the actual prevention of vertical transmission pilot program covering the cities of Agadir, Casablanca and Marrakech, HIV testing is offered to all women after a counselling session. The test is never compulsory, and women are free to decline it. Recent data indicate that most women agree to be tested. Confidentiality of HIV status is, in theory, guaranteed in the protocol—but is not always assured in practice. According to a respondent for this case study, the only woman who had tested positive in one of the pilot programs was visited at home by a health worker who sought to force her to disclose her HIV status to her husband.

#### **4. INFANT FEEDING GUIDELINES AND TRENDS**

In Morocco, about one third of mothers exclusively breast-feed their babies within the first six months of life<sup>28</sup>. The MoH's position on infant feeding for HIV-positive mothers is clear: breast-feeding is contraindicated. In Morocco, it is estimated that 80 percent of the population (99 percent of those in urban areas and 56 percent of rural-dwellers) have access to safe drinking water sources<sup>29</sup>; as such, formula feeding is likely to be appropriate for babies born to HIV-positive women if they receive adequate counselling in safe formula preparation.

All mothers interviewed for this report said that treatment educators carefully explained all relevant aspects of replacement feeding, including how to prepare bottles, after they were informed of their HIV status. Formula is provided free of charge as long as the child needs it in three cities only (Casablanca, Marrakech, and Agadir) as part of recently initiated pilot programs. Elsewhere in the country, formula may be provided by hospitals or NGOs depending on their capacity; this means, however, that some families must buy their own formula, particularly in the cities where there are no NGO programs to support mothers and children.

#### **5. IMPACT OF VIOLENCE AND STIGMA**

In the cultural and religious context of Morocco, PLWHA are sometimes considered “sinners” because of the link between HIV and sexuality. Such attitudes underpin and reinforce the relatively high levels of HIV-related

28 As cited in a speech by Aloys Kamuragiye, the UNICEF representative in Morocco, during the 4th Regional Forum on Media and the Rights of Children, 28 November 2008.

29 UNICEF, State of the World's Children Report, 2006.

*“When I was giving birth in the clinic, the entrance to my room was marked ‘HIV+ patient’. I felt that nurses treated me differently than other women. Some have refused to change my sheets.”*

**36-year-old HIV-positive woman**

stigma and discrimination in the country. As a result, the majority of PLWHA avoid disclosing their HIV status to their families and closest friends. It was only in 2005 that an HIV-positive person (a woman) publicly disclosed her status – on TV, as it turned out.

Women living with HIV seem to face double stigma because of their status and their gender. For many Moroccans, contracting HIV is a sign that a woman has acted immorally and inappropriately. A double standard exists because although unmarried or extramarital sex is mostly accepted for men, women are expected to remain virgins until marriage and face great risk of violence or abuse if engaged in adultery. According to NGO respondents, many HIV-positive women have been abandoned by their husbands, which contrasts sharply with the fact that in general women care for their HIV-positive husbands. The fear of stigma is a major barrier for women to get tested.

Another challenge stems from the fact that HIV-related stigma and discrimination in health services are far too common. According to the preliminary results of a study carried out by ALCS, and to be published in the coming months, most discrimination actually occurs in health settings. This does not necessarily mean that health workers are more stigmatizing or intolerant than the rest of the society, but the impact is far greater because health care facilities are supposed to be nonjudgmental and open to all. Many of the women interviewed for this case study said they had experienced stigmatizing behaviour, including delays in attention or refusal to provide care, from health workers.

In most cases such behaviour occurred in antenatal care facilities, not in HIV-specific care structures. This proves that with adequate training, the attitudes and actions of medical personnel can improve immensely. It also points to a need to provide HIV training to staff throughout the health care system in order to reduce stigma and discrimination.

## **6. ASSESSING THE WORK OF GLOBAL AGENCIES**

The French organization ESTHER was the first external partner to support prevention of vertical transmission in Morocco. The organization helped organize the launch of the pilot study in Rabat by providing funding, training and technical assistance. Today, the organization supports HIV care and treatment for adults and paediatric services in four cities of the country.

UNICEF and UNAIDS have played a major role in prevention of vertical transmission in Morocco. They have offered assistance to draw lessons from the pilot study initiated by ESTHER and to develop a strategy adapted to the Moroccan context. The two agencies are also strong

partners of the MoH-supported prevention of vertical transmission pilot program. They have a support role and provide the necessary technical assistance for the development of the protocol through diverse consultancies as well as the organization of national workshops and trainings.

The Global Fund is the major international donor of HIV programs in Morocco, supporting 46 percent of the cost of the national AIDS strategy. It provides funds for both the government and civil society to implement treatment and prevention programs. The country is currently implementing its second Global Fund program<sup>30</sup>, to which a prevention of vertical transmission component was added in 2008. The funds from this component are being used to purchase equipment and supplies (including reagents) for the MoH's prevention of vertical transmission pilot program.

International agencies have played an important role in the implementation of prevention of vertical transmission interventions in Morocco as well in terms of advocacy, technical support and funding. However, a lack of coordination among the involved agencies often limits their overall effectiveness. Currently, for example, both UNFPA and UNIFEM are focusing on improving maternal and child health and promoting reproductive health for women and girls. Better coordination between these two organizations could improve and facilitate the transition to the scale-up of prevention of vertical transmission.

## RECOMMENDATIONS

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The following recommendations aim to improve the quality, scale and scope of prevention of vertical transmission services in Morocco:

- UNAIDS and WHO should identify and document best practices from low-prevalence countries to provide guidance in developing and implementing prevention of vertical transmission programs in such settings.
- To date, the National AIDS Program (NAP) has been the only entity involved in prevention of vertical transmission. The engagement of other partners, both governmental and non-governmental, is essential to ensure effective scale-up. The NAP must develop partnerships with:
  - the MoH's maternal and child health<sup>31</sup> sector, because antenatal services play a crucial role in the delivery of prevention of vertical transmission;

<sup>30</sup> Morocco has been awarded two HIV/AIDS grants to date, in Rounds 1 and 6.

<sup>31</sup> Santé Maternelle et Infantile (SMI)

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- other departments and ministries of a social nature<sup>32</sup>; and
- civil society.
- Partners involved in the existing prevention programs targeting women and young girls (the MoH, global agencies, civil society) must evaluate such programs in terms of addressing prevention of vertical transmission issues. An important goal would be to increase the programs' capacity and ability to generate testing demand among pregnant women. The MoH must take the lead in this evaluation.
- The MoH, in partnership with civil society and other government agencies, should develop a clear strategy to scale up IEC about prevention of vertical transmission for women of reproductive age.
- The MoH must conduct research in the frame of the pilot prevention of vertical transmission program to identify a reliable list of potential HIV risk factors for pregnant women.
- The provision of prevention of vertical transmission services requires an integrated approach as part of a package of services offered to pregnant women. The MoH's mother and child health clinics must include HIV testing and counselling for their clients.
- The MoH and civil society must improve understanding and awareness of vertical transmission among obstetricians and gynaecologists in the private sector. This would help promote HIV counselling and increase pregnant women's demand for testing.
- Morocco's family planning program has been relatively successful in birth control. It should be systematically used to educate women of reproductive age about vertical transmission, and about the benefits of VCT for high risk women who are planning to have children in the future.
- Specific materials (posters, brochures and other information materials) must be developed by the MoH and civil society for women and couples. At the same time, specialized materials of a similar nature should be developed for health workers in order to promote prevention of vertical transmission.
- NGOs involved in HIV testing must engage in research to explore the possibility of providing counselling and testing to pregnant women through their existing network of centres, especially in areas where MoH-supported prevention of vertical transmission services are not available.

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<sup>32</sup> Including, for example, the Ministry of National Education, the Ministry of Youth and Sports, the Ministry of Social Development Family and Solidarity, and the National Initiative for Human Development (INDH).

- A national strategy to combat HIV-related stigma must be developed and implemented in partnership between the MoH and civil society. This strategy must target the general public as well as health care providers.
  - The MoH, medical professionals and civil society must collaborate to provide training to personnel at all health care facilities, and not only those involved in prevention of vertical transmission, on HIV awareness and care, ethics, confidentiality, and stigma. The training should also focus on increasing knowledge about specific concerns in prevention of vertical transmission such as safe delivery techniques and ARV prophylaxis.
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# Uganda

By Richard Hasunira, HEPS-Uganda; Aaron Muhinda, HEPS-Uganda; Rosette Mutambi, HEPS-Uganda; and Beatrice Were, AIDS activist

## KEY POINTS

1. Nearly 95 percent of pregnant women attend antenatal care services at least once during their pregnancy, but only 43 percent of all health facilities that provide ANC have integrated prevention of vertical transmission services- a missed opportunity.
2. Many clinics and other sites providing prevention of vertical transmission services experience regular stock-outs of ARVs and prophylaxis medicines due to problems related to inefficiencies in the supply chain and distribution system.
3. Mothers reported feeling they can afford neither exclusive breast-feeding nor the recommended alternatives. Stigma, poor nutrition (among mothers), cultural pressures and general poverty have forced many of them to the more risky mixed feeding practice.
4. The health infrastructure does not have the human or financial capacity to meet the increased demand created by women seeking prevention of vertical transmission services.

## RESEARCH PROCESS AND METHODOLOGY

The data presented in this report were gathered through a review of official documents as well as interviews with 12 key informants representing the national MoH; the Kamwenge District Health Office in western Uganda; the Ogur Health Centre IV in Lira District in northern Uganda; WHO; the Elizabeth Glaser Paediatric AIDS Foundation (EGPAF); CESVI (an Italian NGO); and the East Africa office of the International Community of Women Living with HIV/AIDS. The study team also held two focus group discussions with clients of ANC services in the Kamwenge and Lira districts. A total of 16 women participated in the group discussions. Out of the six who participated in the discussion in Lira, five offered to disclose they were HIV-positive. In Kamwenge, none of the 10 participants disclosed their status.

(Note: "\$" refers to US dollar amounts.)

## 1. BACKGROUND INFORMATION

More than 700,000 Ugandan women are living with HIV. The most recent data (from 2004-2005) indicate a national HIV prevalence rate among women of reproductive age of 6.5 percent. Without any intervention, the MoH estimates that about 30 percent of HIV-positive pregnant women transmit the virus to their babies during pregnancy, labour, delivery or post-partum through breast milk<sup>33</sup>. There thus could conceivably be some 27,300 HIV infections among newborns in 2009, based on estimates of about 1.4 million pregnancies in Uganda in that year<sup>34</sup>.

Nearly 95 percent of pregnant women attend antenatal care (ANC) services at least once during their pregnancy. They do not necessarily have access to comprehensive prevention of vertical transmission services, however, because just 43 percent of all health facilities that provide ANC and delivery services have integrated prevention of vertical transmission. This means that only about 50 percent of expectant mothers were estimated to have accessed prevention of vertical transmission services in the 12 months to June 2007. Between July 2006 and June 2007, a total of 533,436 new ANC clients visited prevention of vertical transmission sites and about 80 percent (419,171) of them received HIV testing, of whom 7 percent tested positive. About 80 percent of those diagnosed with HIV were given ARV prophylaxis for prevention of vertical transmission during pregnancy, and 12,601 babies (42 percent) were given ARVs after delivery.

<sup>33</sup> Programme for Prevention of Mother-to-Child Transmission of HIV, Annual Report (July 2006-June 2008), MoH, p.1.

<sup>34</sup> Interview with William Salmond, country director, Elizabeth Glaser Pediatric AIDS Foundation.



The MoH and UNICEF initiated a pilot prevention of vertical transmission program at three hospitals in Kampala in 2000<sup>36</sup>. In 2001, the MoH drafted a five-year scale-up plan, with a target of reducing transmission by 25 percent by 2005 through the provision of a comprehensive package of services to HIV-positive mothers, their spouses and their newborns<sup>37</sup>. The plan was to establish prevention of vertical transmission services in at least one health facility per district by 2004 and then scale up to Health Centre IVs<sup>38</sup> by 2005. The ministry upgraded the scale-up plan to a national prevention of vertical transmission policy in May 2003. The policy was last revised in August 2006.

## 2. STATUS OF SERVICE DELIVERY AMONG AND FOR WOMEN

The MoH currently implements the prevention of vertical transmission policy through the Sexually Transmitted Diseases (STD)/AIDS Program. The policy provides for the four prongs of comprehensive services: primary prevention; family planning for HIV-positive women; prevention of mother-to-child transmission; and care and support for HIV-positive expectant mothers and their families. The national strategy focuses on integrating these services into the reproductive health service package; thus prevention of vertical transmission services in Uganda are provided in the general context of sexual and reproductive health services<sup>39</sup>. The entry point for prevention of vertical transmission services is antenatal care, which is provided by accredited public, mission (NGO) and private facilities at the level of Health Centre III and above<sup>40</sup>. Only a few Health Centre IIIs currently provide prevention of vertical transmission services.

The basic package for prevention of vertical transmission involves testing mothers and their partners for HIV and helping them make safe infant feeding choices. At higher levels of service provision, additional diagnostic tests are offered, ART and/or ARV prophylaxis are made available, and ancillary support such as food supplements and insecticide-treated mosquito nets may be offered.

35 Programme for Prevention of Mother-to-Child Transmission of HIV, Annual Report (July 2006-June 2008), MoH, p.9.

36 Bajunirwe F., et. al (2004): "Effectiveness of nevirapine and zidovudine in a pilot program for the prevention of mother-to-child transmission of HIV-1 in Uganda," African Health Sciences, Vol 4, No.3.

37 Programme for Prevention of Mother-to-Child Transmission of HIV, Annual Report (July 2006-June 2008), MoH.

38 In Uganda's health structure, a Health Centre IV is at the level of health sub-district and is the lowest referral facility, just below the level of a hospital.

39 Interview with Dr. Godfrey Esiru, national PMTCT coordinator, MoH.

40 In Uganda's health structure, a Health Centre IV is at county level; Health Centre III at sub-county; a Health Centre II at parish level; Health Centre I at village/community level.

The chart below provides a summary of key elements of the prevention of vertical transmission package and the level(s) at which they are provided.

	ANC	IYCF	HIV testing	IPC	PNC	sdN	AZT +sdN	AZT+3TC +sdN	HAART
<b>HC II Basic package</b>	√	√	+	+	+	+	-	-	-
<b>HC III Intermediate package</b>	√	√	√	√	√	√	+	+	-
<b>HC IV/Hospitals Comprehensive package</b>	√	√	√	√	√	√	√	√	√

**KEY:**

- HC** = Health Centre  
**IYCF** = integrated infant and young child feeding counselling  
**ANC** = antenatal care  
**IPC** = intra-partum care  
**PNC** = post-natal care  
**sdN** = single-dose nevirapine  
**AZT** = zidovudine  
**3TC** = lamivudine  
**HAART** = highly active antiretroviral treatment  
**√** = service is provided  
**-** = service only available in some of the facilities  
**-** = service not provided at that level

Not all of these services are easily accessible, however. Comprehensive prevention of vertical transmission services are not readily available to all women and children who need them in Uganda, especially in remote rural areas as well as the northern region, which is in a post-conflict situation<sup>41</sup>. Many clinics and other sites providing prevention of vertical transmission services experience regular stock-outs of ARVs and prophylaxis medicines due to problems related to inefficiencies in the supply chain and distribution system.

Counsellors ordinarily give HIV-positive mothers the option to formula-feed or breast-feed, but it is almost routine for mothers to choose exclusive breast-feeding because it is what is nearest to what is possible<sup>42</sup>. The fact is that most mothers in Uganda, and especially those in post-

46 Interview with Dr. Godfrey Esiru, national PMTCT coordinator, MoH.

47 Interviews with Dr. Laura Kaddu, CESVI, and Dr. Vincent Mubangizi (DHO, Kamwenge), and findings from focus group discussion in Kamwenge.

48 Interviews with Dr. Godfrey Esiru (MoH), William Salmond (EGPAF), Dr. Vincent Mubangizi (Kamwenge DHO), and Mary Frances Okello (Ogur Health Centre).

*“One of the biggest barriers to women utilizing PMTCT services is limited male involvement. The program mandates husbands to accompany their wives when they go for ANC services and HIV testing, but women are not taught how to convince their partners to go with them or how to disclose a positive test to them. And don’t forget, some pregnancies don’t involve men who are visible or nearby; some may be a result of rape, some fathers deny responsibility, and some are no longer living. In general, the program demands too much from the woman.”*

Florence Buluba, ICW East Africa

war northern Uganda, currently cannot afford infant formula. On the ground, among the women interviewed, there was a feeling among pregnant women that their breast milk was insufficient due to moderate malnourishment, and they were likely to try to supplement it with other feeding, a step that eliminates the risk-protective factor of exclusive breast-feeding.

The health system does not provide free infant formula, the first recommended infant feeding option for women who might need it. Another major challenge is that the health infrastructure and staff do not have the human or financial capacity to meet the increased demand created by women seeking prevention of vertical transmission services.

#### **PREVENTION OF UNINTENDED PREGNANCIES**

Prevention of unintended pregnancies, even for women in the prevention of vertical transmission program, is the responsibility of family planning clinics within health facilities. Yet the options offered at family planning clinics for avoidance of unintended pregnancies are limited<sup>43</sup>. Antenatal clients at Ogur Health Centre in Lira District complained that they were offered only one brand of contraceptives – Pilplan and Injectaplan, which some women perceive to have high side-effect profiles – and male condoms, the use of which is not necessarily in women’s control<sup>44</sup>.

#### **PROVISION OF SERVICES FOR HIV-POSITIVE MOTHERS, THEIR PARTNERS AND THEIR FAMILIES**

Care and support for mothers and their infants is one element of the national prevention of vertical transmission policy that appears to have received particularly substandard attention. The programs to which mothers are supposed to be referred for nutritional support no longer exist<sup>45</sup>. From the focus group discussions, it emerged that most ordinary mothers feel they can afford neither exclusive breast-feeding nor the recommended alternatives. Stigma, poor nutrition (among mothers), cultural pressures and general poverty have forced many of them to the more risky mixed feeding.

#### **BARRIERS TO COMPREHENSIVE SERVICE DELIVERY AND LESSONS LEARNED**

Findings indicate that shortages of health workers and infrastructure and supplies are the most critical barriers to scaling up a comprehensive set of prevention of vertical transmission services in Uganda. The prevention of vertical transmission policy provides for the roll-out of services up to the level of Health Centre III (sub-county level). However, according to the MoH, only 53 percent of all HC IIIs were providing prevention of vertical transmission services by June 2007 due to a shortage of health workers to provide such services at that level.

<sup>43</sup> The policy guidelines do not specify which family planning methods should be available at clinics.

<sup>44</sup> Focus group discussion held at Ogur Health Centre in Lira District on 30 January 2009.

<sup>45</sup> Focus group discussions in Lira (30 January 2009), and Kamwenge (23 January 2009).

It is also important to recognize that measuring coverage on the basis of the proportion of health centres providing prevention of vertical transmission services masks inequalities in the distribution of prevention of vertical transmission sites because distribution of health centres is not uniform across the country. In districts with few and scattered facilities, particularly those in Karamoja and northern regions, long distances to facilities limit access to services by expectant mothers<sup>46</sup>.

Other notable barriers to women utilizing prevention of vertical transmission services include medicine stock-outs, limited male participation and involvement, and HIV-related stigma and discrimination.

#### NOTABLE LESSONS LEARNED INCLUDE THE FOLLOWING:

*“The government has not given prevention the weight it deserves; it focuses too much on treatment. Food supplements are far cheaper than ARVs, so why can’t we put more money into food supplements for six-month-old babies to save their lives?”*

**Dr Vincent Mubangizi, district health officer, Kamwenge District**

- If accompanied by referral information and resources, outreach HIV testing tends to increase uptake of prevention of vertical transmission services and male participation. CESVI’s outreach-referral project in the Karamoja region’s Abim district and that of Catholic Relief Services (CRS) in western Uganda have resulted in an increase in women enrolling for prevention of vertical transmission. About 39 percent of individuals tested in these projects were male<sup>47</sup>. (Both projects have subsequently ended, although CESVI reportedly is planning to initiate a similar one in northern Uganda. Resource constraints, both human and financial, have hindered efforts to implement such projects over the longer term.)
- The implementation of the prevention of vertical transmission program has supported improvements in the quality of antenatal and delivery care. Vital training has been made available to health care personnel at facilities where the program is being implemented. Some facilities have also had their infrastructure renovated to create space for VCT services, including laboratories. EGPAF, for instance, allocates \$80,000 annually to each of 27 districts in which it operates, with the money targeted to support reproductive health programs<sup>48</sup>.
- Uganda’s experience with prevention of vertical transmission service delivery to date has demonstrated that coordination of the various service providers is necessary to avoid duplication and to ensure that adequate services are rolled out for hard-to-reach populations. The MoH has allocated distinct parts of the country for various NGOs to focus on. However, although this effort has successfully distributed services, effective coverage seems to vary with the capacity of the service provider. For example, EGPAF, which provides services directly

<sup>46</sup> Interview with Dr. Godfrey Esiru, national PMTCT coordinator, MoH. Interviews with Dr. Laura Kaddu, CESVI, and Dr. Vincent Mubangizi (DHO, Kamwenge), and findings from focus group discussion in Kamwenge.

<sup>47</sup> Interviews with Dr. Godfrey Esiru (MoH), William Salmond (EGPAF), Dr. Vincent Mubangizi (Kamwenge DHO), and Mary Frances Okello (Ogur Health Centre).

<sup>48</sup> Interviews with William Salmond (EGPAF) and Dr. Betty Mirembe (EGPAF).

to 64 percent (about 450,000 of 700,000) of prevention of vertical transmission clients, operates in only 33 percent (27 of 81) of the country's total districts<sup>49</sup>.

### 3. HIV TESTING: ACCESS AND OTHER ISSUES

HIV testing services are on average widely available in Uganda. (Other key diagnostic services, particularly CD4, viral load and organ function tests, are less commonly available, however.) Rapid HIV tests are available in both facility and outreach settings. In public facilities, HIV tests are free; in private not-for-profit facilities receiving support from government, clients pay for "consultation"; while private facilities charge direct fees<sup>50</sup>. HIV testing is voluntary in Uganda, but a provider-initiated policy is utilized in the prevention of vertical transmission program. This means that although HIV tests are strongly encouraged, pregnant women can decline (e.g., opt out). However, according to several respondents and focus group participants, it is difficult if not impossible for pregnant women to refuse an HIV test. Many said that an HIV test is in fact "a must" for pregnant women who visit health centres for ANC.

Where VCT services and counsellors are available, expectant mothers are provided adequate information on the benefits of testing for HIV for themselves and their babies. In such locations, uptake of services is higher because clients generally understand that an HIV test is just one of the various tests they should undertake for their own good and for the good of their babies. In remote and hard-to-reach rural areas, however, including in much of the north, the information mothers receive may not be adequate due to capacity limitations in terms of health care personnel and counsellors. In such disadvantaged locations, mothers are more likely to feel coerced into taking an HIV test.

Nevertheless, the opt-out policy, which in 2006 replaced an opt-in policy in which the client had to specifically request an HIV test, has apparently improved access to prevention of vertical transmission services. One indication is that uptake of HIV testing increased from about 60 percent of all new ANC clients in 2004 to 80 percent in 2006-2007<sup>51</sup>.

The official policy provides for confidentiality of test results. The patient registers are in principle kept under lock and key and are supposed to be accessed only by health personnel. However, women visiting prevention of vertical transmission clinics say confidentiality is in effect breached by the public nature of service provision, because some facilities have specific clinics for prevention of vertical transmission clients while other ANC clinics have specific days they serve clients.

49 Interviews with William Salmond (EGPAF) and Dr. Betty Mirembe (EGPAF).

50 "Consultations" and direct fees both require patients to pay, but the amounts differ greatly. Direct fees are usually up to 10 times higher than consultation fees.

51 PMTCT Program Annual Report (July 2006-June 2007), MoH, p.10.

#### 4. INFANT FEEDING GUIDELINES AND TRENDS<sup>52</sup>

The national prevention of vertical transmission policy officially recommends that HIV-positive mothers opt for replacement feeding if it is affordable, feasible, acceptable, sustainable and safe (AFASS). Yet at the same time the policy acknowledges that the majority of Ugandan mothers cannot be expected to meet AFASS standards because of the high levels of poverty, low status of women, stigma and an almost universal breast-feeding culture. As such, counsellors are instructed to i) explain to mothers the full implications of each choice for feeding, and ii) clearly indicate that exclusive breast-feeding for up to six months is the preferred option for mothers whose replacement feeding environment may not be AFASS.

*“We refer the mothers who test positive to the ART clinic, but some never show up there or ever return here for ANC. Stigma is a big problem; people are afraid of being seen at the ART clinic because everyone will conclude they have HIV. We don’t have funds to follow them up and we don’t know where they go next and where they deliver their babies.”*

**Midwife at Padre Pio Health Centre, Kamwenge District**

In practice, however, the main challenge is that most mothers are unable or unwilling to be consistent one way or another in terms of exclusive breast-feeding or exclusive alternative feeding. A mother may decide to breast-feed exclusively, but may start giving her infant additional fluids because she does not believe she has enough breast milk. Or she may opt for replacement feeding only, but soon find that she cannot afford formula regularly or faces strong social or family pressure to breast-feed at least some of the time. As one NGO worker observed, “A mother might make a decision to stop breast-feeding early, but when her mother-in-law visits she will breast-feed again.”<sup>53</sup>

#### 6. IMPACT OF VIOLENCE AND STIGMA

Uganda has achieved a high level of awareness of HIV/AIDS, but HIV-related stigma remains a serious problem. HIV-positive mothers face high levels of stigma within the family, in the community and at health centres. Many women are understandably fearful of disclosing their HIV status to family members—particularly husbands and other male partners, who may beat them or force them from their homes even if they themselves are positive or unaware of their own status.

At the community level, HIV-related stigma limits a woman’s freedom to choose how to feed her infant because, given the cultural norm of breast-feeding, it is often assumed that a woman who does not breast-feed is HIV-positive. Even if they are in fact positive, many women do not want their status assumed or known in their communities. In Lira, northern Uganda, respondents reported that women in the prevention of vertical transmission program were rejecting jerry cans provided by a charity because others in the community teased and avoided those seen fetching

<sup>52</sup> This report was finalized prior to the release, in April 2009, of new guidelines from the MoH recommending that all mothers (HIV-positive or not) initiate breast-feeding within one hour after delivery and exclusively feed the baby on breast milk for the first six months. The ministry also stated that mothers should be given the option of continuing to breast-feed for up to two years after birth if other feeding options are not realistically possible or safe.

<sup>53</sup> Statement by Dr. Laura Kaddu (CESVI).

<sup>54</sup> Interview with Mary Frances Okello, HC IV.

water in them<sup>54</sup>. During the focus group discussion with ANC clients in that district, one participant recalled that her neighbours regularly mocked her after learning that she was HIV-positive.

The situation is often not any better at health facilities. According to one respondent, HIV-positive mothers sometimes feel harassed by health workers who “treat them as though it were a crime to conceive after they knew they were HIV-positive”<sup>55</sup>.

## 7. ASSESSING THE WORK OF GLOBAL AGENCIES

As is the case with the general HIV/AIDS response in Uganda, the prevention of vertical transmission program is entirely donor-dependent for resources<sup>56</sup>. UN agencies, the Global Fund, PEPFAR and other bilateral programs as well as other international non-governmental partners are providing various forms of support, including funds, medicines, training, service delivery, and technical advice. Of the various UN agencies active in Uganda, most support for the prevention of vertical transmission program comes from UNICEF. WHO has been instrumental in technical assistance in policy formulation, developing training and IEC materials, and treatment guidelines.

The increased focus by donors and global agencies on evaluating and increasing prevention of vertical transmission coverage has had a positive impact on service delivery for the most part. Data collected to measure the impact of interventions has helped the MoH re-plan and identify solutions to challenges. In October 2008, for example, a joint review of the prevention of vertical transmission program identified stock-outs of medicines and test kits. The outcome helped UNICEF secure a commitment from UNITAID to donate test kits<sup>57</sup>.

Not all donor interventions are equally useful, however. Some donors provide their funding on budget, while funds from others are provided off-budget. Budget funding is preferable because it facilitates expenditure planning and optimization while at same time promoting a sense of ownership of the national response. Off-budget funding, on the other hand, tends to be based on the priorities of the individual donor in terms of the choice of intervention, timing, scale and location of the intervention. The persistent use of off-budget funding by some donors has to some extent diverted attention from essential elements of the health system which need to be strengthened. Donors generally do not provide funds for infrastructure development and staffing, which currently are the biggest barriers to the scale-up of prevention of vertical transmission services. This had led to situations in which access to vital materials and

55 Interview with Florence Muluba (ICW) and experiences reported during focus group discussions in Kamwenge and Lira districts.

56 Source: Dr. Godfrey Esiru (MoH).

57 Interview with Dr. Godfrey Esiru (MoH).

supplies has been denied; for example, the Clinton Foundation has in the past provided drugs for children that never reached prevention of vertical transmission centres because National Medical Stores (NMS) did not have adequate resources to distribute them<sup>58</sup>.

## RECOMMENDATIONS

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The following recommendations are aimed at improving access to, and the quality of, comprehensive prevention of vertical transmission services for all women and children and need:

- The Ugandan government should relax its staffing ceilings and mobilize resources to improve staffing at lower-level health centres. It should also provide health workers incentives to work in remote, hard-to-reach locations.
- The Uganda AIDS Commission in partnership with civil society organizations should devise new communication strategies to reduce HIV-related stigma and increase male participation in reproductive health through a systematic outreach/home-based mobilization program.
- The Uganda AIDS Commission should mobilize and encourage HIV-positive mothers to form or join psychosocial support groups that can also help them engage in income-generating activities.
- The Ugandan government should privatize the national medicine distributor, NMS, to improve efficiency and minimize medicine stock-outs at prevention of vertical transmission sites.
- The MoH, the Uganda AIDS Commission and non-governmental service providers should streamline reporting by initiating a Web-based format to improve access to quality data for program monitoring and evaluation. This step would also help facilitate efficient distribution of drugs, test kits and other supplies.
- The Ugandan government, the World Bank and the Global Fund should focus assistance and resources on strengthening the Ugandan health system, including the development of infrastructure in locations where it is thin and/or scanty, and equipping laboratories.
- The Ugandan government should work with multilateral organisations and programs (such as UNICEF, UNAIDS and PEPFAR) and other bilateral programs and international partners to step up their assistance in providing and distributing test kits to all prevention of vertical transmission centres in the country.
- The MoH should initiate an anti-stigma program targeting all health workers. Such a program should focus on providing extensive

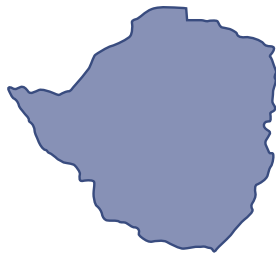
58 Source: William Salmond (EGPAF)

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information about HIV prevention and treatment and include a discussion on the need to recognize the legal and human rights of PLWHA.

- The MoH should ensure that all health care workers receive adequate training in breast-feeding management and counselling, particularly as it pertains to HIV-positive mothers. This is necessary to ensure that all expectant mothers understand the potential risks and benefits of all options and feel as though they can make realistic choices that will help keep their infant as well-fed and healthy as possible. It is especially important that health care workers are familiar with the new MoH guidelines, announced in April 2009, that recommend exclusive breast-feeding for the first six months of every infant's life.
  - The MoH and non-government service providers should mobilize resources for nutritional support for replacement feeding for babies born to HIV-positive mothers who have registered for prevention of vertical transmission services.
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# Zimbabwe

By Matilda Moyo, Pan African HIV/AIDS Treatment Action Movement (PATAM); Caroline Mubaira, Community Working Group on Health (CWGH); and Martha Tholanah, Network of Zimbabwean Positive Women (NZPW+)

## KEY POINTS

1. Zimbabwe's HIV prevention and treatment efforts, including the initiation of new patients on ART, were essentially suspended in the second half of 2008 because of ongoing political and economic turmoil and a strike among health workers that started in October 2008 and closed many of the country's leading hospitals for more than three months.
2. The number of home deliveries increased in 2008, largely in tandem with the freefalling economy. As a result, far fewer mothers and their children had access to crucial antenatal care and prevention of vertical transmission services.
3. Health care workers and civil society actors appear not to be consistently and fully aware of infant feeding guidelines and are therefore unable to help women make realistic and fully informed decisions.

## RESEARCH PROCESS AND METHODOLOGY

The research process included interviews with health ministry officials, hospital staff, managers of NGOs, representatives of UN agencies, medical practitioners, HIV-positive women who recently accessed the prevention of vertical transmission program, and PLWHA involved in advocacy work. Two focus group discussions were also conducted, in Gweru (10 people) and Chitungwiza (eight people). Members of the country team also reviewed key policy documents and monitored the local media for policy changes. (Note: Unless specified otherwise, "\$" refers to US dollar amounts.)

## 1. BACKGROUND INFORMATION

An estimated 131,000<sup>59</sup> patients were on ART in Zimbabwe by the end of 2008, a number that falls far short of that year's national target of 180,000. Of those on ART, 74,474 were women and 11,488 were children<sup>60</sup>. One of the reasons that more women than men are on ART is that prevention of vertical transmission is a primary entry point to ART in Zimbabwe, and prevention of vertical transmission, until recently, was arguably the best-performing HIV prevention and treatment program.

The country's HIV prevention and treatment efforts were essentially suspended in the second half of 2008 because of ongoing political and economic turmoil and a strike among health workers that started in October 2008 and closed many of the country's leading hospitals for more than three months. By the fourth quarter of 2008, no other services, such as diagnostic tests and treatment of OIs, were being offered; as a result, no new patients were being initiated on ART.

In January 2009, Minister of Health and Child Welfare Dr. David Parirenyatwa announced that the government planned to place 290,000<sup>61</sup> people on ART by December 2009, a target many dismissed as impractical given past failures and resource constraints. As one health ministry official noted, "We cannot put 160,000 people on treatment in less than 11 months." Unfortunately, the need continues to climb across the country. It is estimated that 1.3 million people are living with HIV and

59 2008, fourth quarter report. Summary presentation to the Operations and Disbursement Committee of the NAC Board.

60 Interview with Dr. Owen Mugurungi, head of the MoH's AIDS and TB Unit.

61 Dr. David Parirenyatwa, Minister of Health and Child Welfare, cited on Zimbabwe Broadcasting Corporation (ZBC) news bulletin, 5 January 2009.

*“Zimbabwe’s health professionals are working under intense pressure and stress. They have too much to do, poor pay, a critical lack of supplies. What they are meant to do as doctors is just impossible.”*

**Peter Iliff, Zimbabwe Association of Doctors for Human Rights**

that at least 260,000 are in need of ART now<sup>62</sup>. National HIV prevalence among people aged 15 to 49 is 15.6 percent; the comparable figure among women is 21.1 percent<sup>63</sup>.

The constantly deteriorating economic situation has made life extremely hard for PLWHA, even those who are already on ART. Health centres have started charging fees in foreign currency, thereby pushing health services further out of reach for most people in an economy where the majority earn the local currency and live on less than \$2 a day.

Meanwhile, a cholera outbreak that killed more than 3,000 people between August 2008 and January 2009 diverted attention and resources from other health needs. This has resulted in further neglect of the crumbling health system, including HIV/AIDS services.

## **2. STATUS OF SERVICE DELIVERY AMONG AND FOR WOMEN**

For a long time prevention of vertical transmission was the only strength of the otherwise severely weakened Zimbabwean health care system. The advent of provider-initiated counselling and testing (PICT), introduced in 2007 and currently being rolled out, bolstered and temporarily improved uptake of the prevention of vertical transmission program. The government estimated prevention of vertical transmission coverage to be around 80 to 90 percent towards the end of 2008<sup>64</sup>, but the rapid scale-up was interrupted by the health workers’ strike and the worsening economic situation. That development further jeopardizes the stated goal of 100 percent prevention of vertical transmission coverage in the Zimbabwe National HIV and AIDS Strategic Plan (ZNASP) 2006-2010.

According to the 2008 fourth quarter report by the chief executive officer of the National AIDS Council (NAC), Dr. Tapuwa Magure, the number of women visiting antenatal clinics declined towards the end of the year. Also, the number of newborns exposed to HIV who receive nevirapine or other ARV prophylaxis is much lower in comparison with the number of mothers who were offered ARV prophylaxis. This gap has two main causes: limited follow-up of women who give birth at home, and many pregnant women’s limited access to ARV prophylaxis for their newborns.

Such shortcomings in program delivery can be seen in the brief analysis below of each of the four components of the country’s prevention of vertical transmission program: primary prevention; prevention of unplanned pregnancies; prevention of mother-to-child HIV transmission; and care and support for mothers and babies.

62 Dr. David Parirenyatwa, Minister of Health and Child Welfare, 2007.

63 UNAIDS Fact Sheet, World AIDS Day 2007.

64 Interview with Dr. Owen Mugurungi, head of the MoH’s AIDS and TB Unit.

## PRIMARY PREVENTION

According to Albert Manenji, finance director at the National AIDS Council (NAC), Zimbabwe's behaviour-change strategy focuses on the promotion of condom use and abstinence. Implementers of the strategy assess the drivers of HIV in each community and then design appropriate responses. Activists, however, believe HIV prevention efforts among women are hindered by the severely limited availability of women-controlled prevention mechanisms, notably female condoms.

Concerns have also been raised about the effectiveness of prevention efforts among young girls in the current economic and political context. Hege Wagaan, a partnership advisor at UNAIDS in Zimbabwe, observed that although in the past girls could obtain useful prevention information at school through subjects such as life skills, such services have been compromised by a high drop-out rate among girls and the mass turnover of trained teachers. The link between the deterioration of the education system and the impact of HIV prevention efforts cannot be ignored.

Mary Sandasi, director of the Women and AIDS Support Network (WASN), noted as well that the deteriorating economic environment and lack of employment opportunities had forced an increasing number of women and girls into commercial sex work, thereby increasing their vulnerability to HIV infection. The impact of HIV prevention efforts has also been hobbled by the mass migration of people to neighbouring countries; this diaspora has exposed many children to sexual abuse and neglect by guardians. In addition, some of the young people are sexually abused en route to neighbouring countries. Young people in such situations are highly vulnerable to HIV infection in an environment where post-exposure prophylaxis is not easily available and accessible to victims of sexual assault<sup>65</sup>.

## PREVENTION OF UNPLANNED PREGNANCIES

The difficult environment has also affected family planning services such as access to contraception to prevent unintended pregnancies among HIV-positive women. Women and girls rarely have consistent access to condoms and other secure forms of contraception because distribution systems are failing, largely due to human resource challenges.

Women in Chitungwiza said they could no longer get free contraceptives from clinics because they were being diverted to the parallel market by corrupt health care workers<sup>66</sup>. Rosa Nyathi, an activist, further noted that the increased use of foreign currency in the economy had worsened the situation; she said, for example, that a Norplant implant at a government hospital currently cost \$32<sup>67</sup>.

65 Interview with Mary Sandasi, executive director of the Women and AIDS Support Network (WASN).

66 Focus group discussion with women from Utano Community Center, Chitungwiza, 28 January 2009.

67 Interview with Rosa Nyathi, an activist at the Zimbabwe HIV/AIDS Activists' Union (ZHAU).

Officials within the MoH said that the greatest weakness of the country's national family planning program was its dependence on external funding. The program virtually folded after donors started scaling back aid because of the political environment.

#### **PREVENTION OF HIV TRANSMISSION FROM MOTHER-TO-CHILD**

In line with the ZNASP, HIV testing is routinely offered to every woman who receives antenatal care. This effort has been further supported by the introduction and roll out of PICT, which assumes HIV tests will be administered unless women specifically “opt out”. Therefore, treatment is offered to all women who test positive for HIV and are not on ART. Most women receive a single dose of nevirapine during labour, while their babies receive liquid nevirapine within 72 hours after birth.

Dr. Owen Mugurungi, head of the MoH's AIDS and TB Unit, said that a more efficacious regime is being pilot-tested at selected centres. Under this arrangement, an HIV-positive expectant mother receives AZT from 28 weeks until delivery, coupled with a single dose of nevirapine during labour. The baby receives a single dose of nevirapine after birth and both the mother and child get Combivir (AZT+3TC) for seven days following birth. Mugurungi added, “All pregnant women should be offered HIV counselling and testing as well as a CD4 count test for those who are HIV-positive. If the CD4 count is 350 or below, they are immediately initiated on treatment.”

The prevention of vertical transmission program is institution-based and links women to facilities from the lowest community health centre to the highest referral hospitals as part of a continuum of services. It has been integrated into all ANC units, and staff who conduct deliveries have been trained in counselling, testing and drug administration. Clients have an option to choose between the maximum and the minimum package. The maximum package consists of counselling, testing, provision of ARV drugs and monitoring of the patient, while the minimum package only offers counselling<sup>69</sup>.

An assessment of what is happening on the ground revealed that the quality and level of prevention of vertical transmission services offered at rural and urban health centres differs, with most services concentrated in urban areas even though 70 percent of the population is rural-based. For example, in Kwekwe district only two of the seven prevention of vertical transmission sites that offer the maximum comprehensive package are in rural areas.<sup>70</sup>

68 Interview with Dr. Owen Mugurungi, head of the MoH's AIDS and TB Unit.

69 Interview with Gretel Mahere, a district nursing officer in Kwekwe, and focus group discussion with members of Volcano of Hope Support Group in Gweru.

70 Interview with Gretel Mahere, a district nursing officer in Kwekwe.

The overall public prevention of vertical transmission program has been severely compromised since early 2008 because of the collapse of the health delivery system, a situation characterized by lack of resources, dilapidated infrastructure and staff shortages. Many interviewees noted that when the country's systems were functioning effectively, the prevention of vertical transmission program was among the best in the southern African region. When it was operating well, structures were in place and they were supported by policy. Staff were trained and there was good monitoring while the MoH provided constant feedback and gathered data about the status of the program at each stage of the comprehensive care provision. However, by January 2009 the program was mostly a shadow of its former self across the entire country, even in the largest cities.

### **CARE AND SUPPORT FOR WOMEN, THEIR CHILDREN AND THEIR PARTNERS**

In 2003, Zimbabwe introduced a PMTCT+ program, which looks beyond protecting infants from HIV and focuses more broadly on the provision of treatment and care for mothers and their families. However, this program has not been very effective due to resource constraints. Dr. Ima Chima of EGPAF pointed to a paediatric ART survey conducted by her organization revealing poor linkages between prevention of vertical transmission and ART sites. In addition, she said, there is no way of following up children who have been exposed to HIV<sup>71</sup>.

Mugurungi said the Clinton Foundation is supporting the purchase of paediatric drugs and that although the medicines are available, infant diagnosis remains a challenge. PCR tests, for example, are only available at a few central hospitals. Efforts are being made to follow up on babies born to HIV-positive mothers so that their status can be checked when they come for immunization. If the baby is HIV-positive, ART is initiated immediately.

Meanwhile, patients are being “herded” to church-related mission hospitals in rural areas, where health care workers generally display a better work ethic than do those in urban facilities. This is so even where public facilities that are supported by the Global Fund are better equipped and resourced than the mission hospitals, especially in the wake of the long strike that ended (at least technically) in January 2009<sup>72</sup>. The Global Fund currently supports facilities in 22 districts, all in rural areas. Money made available through Round 8 will be used to expand Global Fund-supported facilities into other districts, including in urban areas.

71 Dr. Ima Chima, findings from the Elizabeth Glaser Paediatric AIDS Foundation's National Paediatric ART Site Survey 2007. Presentation at Safaids Discussion Forum.

72 The health care workers' strike that began in October 2008 officially ended in January 2009. However, reports through March 2009 indicate that although health personnel are showing up for work again, they are not necessarily working. This implies that the strike persists for all intents and purposes.

Over the years, efforts have been made to establish referral systems linking clinics specializing in prevention of vertical transmission, VCT, OIs, TB, and STIs, all of which are entry points for expanded care. Anyone who tests positive at any of these points receives psychosocial support and is referred for ART<sup>73</sup>. In addition, the MoH now has prevention of vertical transmission focal persons in some districts.

However, according to Bernard Nyathi, president of the Zimbabwe HIV/AIDS Activists Union (ZHAAU), the referral systems are not working well due to limited resources.<sup>74</sup> For example, the government ART program did not enrol new patients during the health workers' strike; therefore, it is pointless to refer people to centres where they cannot be treated. Lack of treatment access means there is little incentive for getting tested, including for pregnant women.

### SUCCESS STORIES

All health care services, including those related to prevention of vertical transmission, are struggling to prevent further decline in access and effectiveness. There are some success stories that deserve mention, however, including the following (all of which were mentioned by respondents):

- According to Manenji from NAC, no patients are required to pay for services at facilities in rural areas that benefit from the Global Fund and Expanded Support Program (ESP), which is a pool fund by a number of bilateral donors (see below). This has resulted in universal access targets being reached in some districts; for example, in January 2009 there was no one on the ART waiting list in Matabeleland South province. (It is important to note, however, that this is the province that has seen the largest number of young people crossing into South Africa and Botswana for economic reasons.)
- Prevention of vertical transmission services in Chitungwiza reportedly are working well because male partners are involved in programs. Where men are incorporated into programs, incidents of violence and stigma are reduced. The mother is also assured of support should she decide not to breast-feed<sup>75</sup>. The MSF polyclinic in Epworth has a counselling centre that seeks to include all family members, including fathers, mothers and children. This has worked well in helping families support each other, accept their HIV status and enrol for prevention of vertical transmission – although the program is overloaded<sup>76</sup>.

73 Dr. Ima Chima, findings from the Elizabeth Glaser Paediatric AIDS Foundation's National Paediatric ART Site Survey 2007. Presentation at Safaids Discussion Forum.

74 Interview with Bernard Nyathi, president of Zimbabwe HIV/AIDS Activists Union (ZHAAU).

75 Focus group discussion with women from Utano Community Center, Chitungwiza, 28 January 2009.

76 Interview with Bernard Nyathi, president of the Zimbabwe HIV/AIDS Activists Union (ZHAAU).

- Betseranai, an NGO in Mberengwa district, uses “PMTCT champions” to mobilize pregnant women and their partners for HIV testing. The use of locally recruited people living with HIV is appropriate and cost effective for the geographical area they cover. They use methodologies appropriate for the level of education and cultural context of the communities they work in. They also promote healthy behaviours in communities in terms of infant feeding.
- Zimbabwe still has one of the best networks for prevention of vertical transmission in the region. It is the only country in southern Africa to record a reduction in HIV prevalence, from over 30 percent in the 1990s to 15.6 percent in 2007, and prevention of vertical transmission contributed towards this. Most HIV-positive mothers who got advice about nevirapine and breast-feeding managed to prevent transmission to their infants, according to Dr. Paul Chimedza, a medical practitioner who specializes in HIV treatment<sup>77</sup>.

*“You cannot run a PMTCT program independently from the overall health program. If the health system falls apart, the PMTCT program will also fall apart.”*

**Hege Wagaan, a partnership advisor at UNAIDS in Zimbabwe**

#### **BARRIERS TO COMPREHENSIVE SERVICE DELIVERY**

Human resource shortages are the major barrier to women accessing prevention of vertical transmission services. While most public-sector health care workers who remain in the country are committed and conscientious, they are trying to function in extremely difficult circumstances. Many of them cannot even make it to work because their monthly salaries cover perhaps four days of transport fares.

Although efforts have been made to improve the remuneration of health workers through the harmonized retention scheme for workers, it is not likely to curb the brain drain. A scheme supported by the Global Fund, the Expanded Support Program (ESP) and other donors involved in health care systems strengthening aims to address distortions in the system where health workers at donor-funded institutions often earn more than their public-sector counterparts. Initiated in August 2008, the scheme covers 22,000 health care workers at various levels and pays an additional allowance to their monthly salary. Although the allowances initially were quite substantial, their value has been sharply eroded by the increased use of foreign currency in the economy. As a result, the current allowances have been described as “miserable” and still do not allow most recipients to cover basic living expenses.

A severe shortage of financial resources has also thoroughly crippled the health delivery system, resulting in a shortage of drugs and equipment as well as the inability to maintain and replace outdated and dilapidated facilities and infrastructure. Frequent stock-outs are experienced in public health centres and clients sometimes have to buy drugs, which should be provided for free.

<sup>77</sup> Interview with Dr. Paul Chimedza, a medical practitioner who specializes in HIV treatment.



Misappropriation of drugs is also a problem. A month's supply of drugs for triple-combination therapy costs about \$200 in the private sector, but is provided free of charge in the public sector. Seizing an opportunity to make money, some workers within the public sector pilfer drugs, reagents and other commodities for resale on the informal market after turning away patients by alleging stock-outs. Another supply-related problem results from the fact that some hospitals use the WHO staging system to place patients on ART, while others are more stringent and insist on CD4 count and liver function tests before placing patients on treatment. As a result, patients flock to hospitals that have less stringent requirements, leading to stock-outs due to demand.

Economic and social obstacles are also important in terms of women's ability to fully utilize all available services. The number of home deliveries increased in 2008 largely in tandem with the freefalling economy. High transport fares and hospital fees, both charged in foreign currency, compounded by the protracted strike by health care workers, have forced women to seek alternative services.

Delivery of services depends on availability and access. While there are government and NGO programs providing free ARVs, frequent stock-outs are experienced at rural health centres. In some cases where treatment is required, therefore, clients have no choice but to buy nevirapine (and many cannot afford it). Health workers at some facilities have resorted to issuing nevirapine to pregnant mothers so they can take the tablet at home once they go into labour. This causes problems as mothers at times take the tablets when they are in false labour, and sometimes other family members (often her husband) will take the nevirapine due to lack of adequate knowledge.

After delivery, women are then supposed to take their newborns to the health facility within 72 hours for the baby's nevirapine dose. However, some fail to raise the money for transport, an increasingly common situation because most services in Zimbabwe can now be obtained only by paying with US dollars or South African rand. Some have sufficient funds for transport, but still cannot reach health centres because transportation is hindered by poorly maintained roads. There is usually no follow-up of women who give birth at home, and many of them do not have access to ARV prophylaxis for their newborns.

It became clear soon after the initiation of the prevention of vertical transmission programs that social and cultural barriers also would hinder uptake. Ensuring male partner involvement and finding creative roles for men is important because failure to secure their support can diminish adherence. NAC, through its partners, is advocating for male participation in the program in order to protect spouses in the context of cultural issues such as breast-feeding<sup>78</sup>.

78 Interview with Albert Manenji, NAC.

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### 3. HIV TESTING: ACCESS AND OTHER ISSUES

Most VCT centres, commonly known as New Start Centres, in Zimbabwe are run by Population Services International (PSI). Facilities are largely accessible and available to the public, particularly in urban areas. However, uptake remains low and, according to the television program “Positive Talk”, only 20 percent of Zimbabwe’s adult population knew their HIV status in 2008<sup>79</sup>.

One reason for the low uptake to date is that many people – particularly women who may be economically disadvantaged – cannot afford even the nominal fee for rapid testing charged by New Start Centres. Several activists also complained that VCT centres do not provide follow-up services themselves but instead refer those who test positive to the public health system for further attention, even when they know treatment is not available there.

### 4. INFANT FEEDING GUIDELINES AND TRENDS

The MoH’s guidelines on infant feeding recommend exclusive breast-feeding for six months followed by abrupt weaning and solid foods – or, for those who can afford it, exclusive breast-feeding for three months followed by formula feeding. The guidelines discourage mixed feeding<sup>80</sup>.

The shortage of trained staff means that many pregnant women do not receive sufficient (if any) advice on infant training. Moreover, even women who are fully aware may not be able to comply with recommendations and/or be consistent with their feeding methods. Zimbabwe is in the midst of a prolonged famine in which more than half the population is in need of food aid. Women who cannot produce breast milk often find it difficult to obtain formula milk because it is not provided free of charge at most prevention of vertical transmission facilities, especially those in the public sector. In January 2009, 400 grams of formula cost \$10 and lasted three to four days, depending on the baby’s eating habits<sup>81</sup>. Some women have resorted to importing formula from neighbouring countries, where it is usually cheaper. However, this option is utilized only by the small number of women who have access to foreign currency and not the majority poor.

In addition, access to safe, clean water remains a problem for people in Zimbabwe, as evidenced by a recent cholera outbreak. A cumulative total of some 100,000 cases of cholera and more than 4,000 deaths had been confirmed between August 2008 and April 2009. The cholera outbreak points to a major challenge in terms of formula feeding because of the need for regular access to clean water to mix the formula. Many HIV-

79 “Positive Talk” television program, 8 February 2009.

80 Interview with Dr. Owen Mugurungi, head of the MoH’s AIDS and TB Unit.

81 Ibid.

positive women therefore have no option but to breast-feed even if they would prefer not to or over a period longer than recommended by most policies.

## 5. IMPACT OF VIOLENCE AND STIGMA

In 2007, the government enacted the Domestic Violence Act, which protects individuals from gender violence. Prior to this, violence against women was usually treated as a domestic issue and the police would not get involved in protecting women from abusive spouses.

That law is quite new, though, and its passage cannot conceal the reality that violence against women has long been among the most significant deterrents to uptake of prevention of vertical transmission. (Gender-specific violence is in fact one reason that many activists are lobbying to change the official name of the PMTCT program to prevention of parent-to-child transmission [PPTCT], a step that they think might ensure greater male involvement<sup>82</sup>.) As a result of violence or the threat or fear of violence, many women who get tested do not collect their results. There have been reports of women being abandoned after testing HIV-positive and reports of violence linked to a woman's HIV status.

Some respondents pointed to a possible silver lining in the economic crisis. They said it appeared that violence against women in general or because of their HIV status was less of a problem in some communities because people are focusing so intensively on the basics in life, such as getting enough food and other necessities.<sup>83</sup>

HIV-related stigma remains strong in Zimbabwe, but several respondents said they perceived a lessening of stigma due to increased openness about HIV, particularly when people in leadership positions disclose their status. PSI has been running a campaign against stigma using community role models such as football players and church leaders, among others, who have disclosed their status and are now open about being HIV-positive. Improved access and greater availability—at least until relatively recently—to treatment also has made more people open about their status, a development that helps reduce societal stigma.

## 6. ASSESSING THE WORK OF GLOBAL AGENCIES

Most UN agencies channel their funding through the government so it is difficult to assess their individual contributions. However, it is clear that agencies such as UNICEF and UNAIDS have maintained a strong presence and contribute significantly in supporting the national response to HIV/AIDS. UNFPA leads the behaviour-change strategy process and covers

<sup>82</sup> Interview with Hege Wagaan, partnership advisor at UNAIDS in Zimbabwe.

<sup>83</sup> Focus group discussion with women at Utano Community Center, Chitungwiza.

*“People are being turned away from OI clinics even when their CD4 counts are low. When a health institution, a government-run clinic, turns away a person with a CD4 count of 35, what are we coming to?”*

**Stanley Takawona, secretary-general of the Zimbabwe HIV/AIDS Activists Union**

36 districts<sup>84</sup>. The Global Fund and ESP have been supporting human-resource retention and the ART program, thereby providing access to treatment for rural populations. Donors have introduced outreach to mitigate the challenges associated with prohibitively expensive transport fares. Some NGOs donate testing kits – although often they are accompanied by few or no reagents.

External support has been useful in shoring up an otherwise collapsed health system, although some respondents said the impact of such support is reduced somewhat because services are often duplicated. In this view, the agencies would be more effective from a collective standpoint if they spread their aid over diverse areas in order to have greater impact<sup>85</sup>. Other observers, however, were far more complimentary. They said the agencies have operated relatively well in a very difficult operating environment, and that even limited success is important. A key obstacle to all donors’ recent efforts was the fact that NGOs were not allowed to operate in Zimbabwe for six months in 2008 after being deregistered by the government. That gap slowed down the work of both the organizations and their supporting partners.

## 7. RECOMMENDATIONS

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As noted throughout this case study, Zimbabwe is currently experiencing an almost unprecedented economic and political crisis that has negatively affected all aspects of society, including the health care system. Improving the delivery of prevention of vertical transmission services therefore depends on a wide range of factors that are not easily quantifiable or even recognizable. The following recommendations should be considered with that caveat in mind:

- Civil society should support the MoH in improving communication and public awareness on prevention of vertical transmission by conducting treatment literacy programs that inform the public about vertical transmission, including where and how key services are available. Such programs also should include clear and objective information about the potential risks and benefits of breast-feeding for HIV-positive mothers, thereby helping many clients make better-informed choices for themselves and their children.
- Civil society should serve as a watchdog, monitoring the government’s efforts and ability to fulfil its responsibility of prevention of vertical transmission provision for all in need and ensuring that money allocated towards prevention of vertical transmission is used for that purpose.

<sup>84</sup> Albert Manenji, National AIDS Council (NAC).

<sup>85</sup> Interview with Angeline Chiwetani, an activist.

- The MoH should speed up the roll out of a more efficacious prevention of vertical transmission regime; improve delivery of ANC services; and strengthen the health care delivery system, including in regards to HIV care and testing. This should include guaranteeing that ARVs are available to everyone for free, as is done with TB drugs.
  - The MoH and partners should strengthen programs that involve males and other family members in prevention of vertical transmission service delivery. Also, traditional birth attendants should receive periodic training and monitoring to keep abreast of developments in prevention of vertical transmission.
  - The Ministry of Finance should allocate adequate funding to the MoH for strengthening the overall health service. The health sector should get the same prioritization that has been given agriculture.
  - The MoH should seek to ensure that guidelines on infant feeding are widely disseminated among the general population in both urban and rural communities. The ministry should also ensure that health care workers and civil society actors not only are aware of the updated guidelines and all issues related to infant feeding, but have information on strategies to help clients make realistic, fully informed choices.
  - The private-sector response needs to be improved, with workplace programs that cater for entire families rather than individual employees, who after all do not exist in a vacuum.
  - Global agencies should commit more resources towards health programs in Zimbabwe. The country receives the least support in the southern African region but has had the most effective programs with limited resources.
  - The donor community could support the MoH in providing formula to HIV-positive mothers who want or need it as part of the prevention of vertical transmission package. This would ensure that feeding options meet the WHO AFASS conditions. The provision of formula must, however, be accompanied by increased humanitarian support aimed at improving and ensuring access to safe, clean water.
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**INTERNATIONAL TREATMENT PREPAREDNESS COALITION**  
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