ELIMINATION WITHOUT VIOLATION

UNAIDS SUPPORTS WOMEN LIVING WITH HIV TO PUT HUMAN RIGHTS, GENDER EQUALITY AND MEANINGFUL ENGAGEMENT OF COMMUNITIES AT THE CENTRE OF VALIDATING ELIMINATION OF MOTHER-TO-CHILD TRANSMISSION OF HIV

Progress towards eliminating new HIV infections among children marks one of the greatest public health achievements of recent times. Globally validating elimination has become a critical milestone in recognizing countries' commitment while encouraging others to accelerate progress. Central to this process is the leadership of UNAIDS and its partners to ensure that elimination never comes at the expense of human rights.

Advance unedited version

Towards an AIDS-free generation

The world has committed to eliminating new HIV infections among children by 2020—a crucial step to bringing about an AIDS-free generation. A global movement to achieve this goal is well underway and has already delivered remarkable gains. Between 2010 and 2015, the number of new HIV infections in children plummeted by 51%,[1] and a growing number of countries are closing in on the benchmark of eliminating mother-to-child transmission of HIV (eMTCT). Such rapid progress is a testament to the power of the AIDS response to bring real and lasting change to the lives of people around the world.

As countries have begun to achieve eMTCT, global validation has become a critical milestone. Independent validation by WHO celebrates countries' achievements legitimizes their claims of elimination and encourages countries to sustain their efforts while motivating others to work towards eMTCT.

To lead this process, WHO, in partnership with UNAIDS, UNFPA and UNICEF, has developed standardized criteria and global guidelines for validation of eMTCT. Recognizing that human rights violations—particularly of women's sexual and reproductive rights—can occur in the name of ending new HIV infections among children, UNAIDS has worked closely with the International Community of Women with Living HIV (ICW) and the Global Network of People Living with HIV (GNP+) in ensuring that human rights, gender equality and community engagement considerations form a central aspect of eMTCT validation. This marks the first time in public health history that protecting human rights has been considered a prerequisite to validating disease elimination.

> *"Elimination of mother-to-child transmission of HIV is a key milestone in our efforts to end the aids epidemic by 2030. Human rights must be respected when pursuing this goal and validation offers a critical lever for ensuring their protection and promotion."*
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> Luiz Loures, Deputy Executive Director, UNAIDS

The Global Plan focuses efforts and accelerates results

In 2011, when almost no children were born with HIV in high-income countries, more than 300,000 were newly infected in poorer countries. To address this injustice, UNAIDS and the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) launched a special partnership to catalyze action for the health and survival of both mothers and babies. With support from other partners, including WHO, UNICEF, countries and civil society, the Global Plan towards the Elimination of New HIV Infections among Children by 2015 and Keeping their Mothers Alive was launched.

The Global Plan has galvanized leadership, engaged front-line communities, and stimulated innovative approaches and new technologies to prevent, diagnose and treat HIV. It has brought together a diverse set of stakeholders, including political leaders, funders, the private sector, women living with HIV and many more; seized political momentum; and set bold targets enabling accountability. The Plan focuses on 21 priority countries[2] that are home to 90% of the world's pregnant women living with HIV, but its guidance is universally applicable. The Global Plan has inspired countries already doing well, and those still in need of critical support, to push for elimination.

[1] Get on the Fast-Track - The life-cycle approach to HIV. UNAIDS, 2016. http://www.unaids.org/sites/default/files/media_asset/Get-on-the-Fast-Track_en.pdf

[2] Angola, Botswana, Burundi, Cameroon, Chad, Côte d'Ivoire, Democratic Republic of the Congo, Ethiopia, Ghana, India, Kenya, Lesotho, Malawi, Mozambique, Namibia, Nigeria, South Africa, Uganda, United Republic of Tanzania, Swaziland, Zambia and Zimbabwe. India was excluded from the final analysis as data for India were not available over the Global Plan period.

Several countries that have met the requirements for eMTCT are now in the phase of validation. UNAIDS has played, and continues to play, a crucial role in this process.

Recognizing the rights at stake

The WHO 2014 guidelines for validation of eMTCT lay out specific thresholds for achieving elimination, including for the rate of new HIV infections in children and levels of service coverage. As current antiretroviral therapies are not 100% effective in preventing mother-to-child HIV transmission, and the epidemic remains widespread, eradication of paediatric HIV is not currently feasible.

Therefore, WHO has defined elimination as reducing the number of new paediatric HIV infections to a level low enough that it no longer constitutes a public health problem.[3] This approach has also been adopted for congenital syphilis, of which mother-to-child transmission can be prevented through simple, low-cost screening and treatment of pregnant women. As the antenatal services to prevent mother-to-child transmission of HIV and syphilis are similar, dual elimination is being pursued to harmonize improvements in maternal and child health.

Yet there was increasing recognition that the validation exercise would need to go beyond simply validating the rate of transmission of HIV from mother-to-child. Around the world, when women access HIV services, they report facing stigma, discrimination and even physical violence (see Box 1). Discrimination against women living with HIV within health-care settings often results in inability to access care, in services that are of poor quality, and, in some instances, mandatory testing, involuntary sterilization or forced abortions. Similarly, criminalization of nondisclosure, exposure to or transmission of HIV can discourage pregnant women from accessing antenatal care for fear that they will test positive for HIV and face prosecution. In a number of countries, HIV-specific laws or existing criminal law provisions could be applied to prosecute HIV exposure or transmission during pregnancy, delivering or through breastfeeding.[4,5]

Actions taken to eliminate new infections among children must always reinforce and promote the human rights of women living with HIV and their infants. Women living with HIV are entitled to enjoy all human rights, including the

Box 1: Discrimination and human rights violations faced by women living with HIV in health-care settings

- 1 in 10 adults living with HIV had experienced discrimination in health-care facilities, in a study across Burkina Faso, Kenya, Malawi, and Uganda.[1]
- The People Living with HIV Stigma Index documented that for women living with HIV:
  - 40% reported being advised against having a child by a health-care professional in Zimbabwe (2014);
  - 8% reported being coerced into having an HIV test in Germany (2011);
  - 4% reported being denied family planning services in Cameroon (2012);
  - 3% reported being denied health services in the previous 12 months at least once in Uganda (2013);
  - 2% reported being denied sexual and reproductive health services in the previous 12 months in Honduras (2014);
  - 6% reported being coerced into terminating a pregnancy in Nigeria (2010);
  - 5% reported being coerced into being sterilized by a health-care professional in Ukraine (2010).[2]

[1] Neuman, M., Obermeyer, C. M., & MATCH Study Group. (2013). Experiences of stigma, discrimination, care and support among people living with HIV: A four country study. AIDS and Behavior, 17(5), 1796-1808;

[2] Selected examples from the People Living with HIV Stigma Index surveys

[3] Global Guidance on Criteria and Processes for Validation: Elimination of Mother-to-Child Transmission of HIV and Syphilis. WHO, 2014. http://www.who.int/reproductivehealth/publications/rtis/9789241505888/en/

[4] Csete J, Pearshouse R & Symington A 'Vertical HIV transmission should be excluded from criminal prosecution' Reproductive Health Matters. 2009 Nov; 17(34):154-62.

[5] Eba PM. HIV-specific legislation in sub-Saharan Africa: A comprehensive human rights analysis. African Human Rights Law Journal 2015; 15; 224-262.

"It is critical that countries and programmes understand that violations of human rights are wholly unacceptable when pursuing clinical benchmarks for PMTCT. Networks of women living with HIV have the right to be involved in decision-making and programming that directly affect their lives. UNAIDS has leveraged its networks to create space for civil society input and ensure that community is involved throughout the validation process."

Rebecca Matheson, Global Director, International Community of Women Living with HIV

right to life, health and non-discrimination; the right to found a family; and the right to information, confidentiality, expression, privacy, association and participation.

Human rights violations in maternal and child health-care settings have long been identified by networks of women living with HIV—something which UNAIDS has given prominence to and works to address.[6] Accordingly, WHO and UNAIDS turned to civil society to jointly assemble rights-related validation criteria. UNAIDS supported ICW and GNP+ in the development of a tool for assessing whether eMTCT had been achieved in a manner consistent with human rights. The tool is an integral part of the validation process, used for the independent assessment of whether a country has met validation criteria and demands that countries give equal importance to the tool as they do for laboratory quality, data quality, costing and programme assessment.

To qualify for validation, countries must be able to demonstrate that eMTCT has been achieved without violating eMTCT-related human rights, gender equality and community engagement principles. The human rights tool also enables countries yet to apply for validation to review whether their eMTCT programmes are addressing these issues. It provides a pragmatic approach to assessing and upholding human rights and is constantly being strengthened.

Never before have human rights been recognized as an integral component of disease elimination and put on an equal footing with other considerations. It represents a landmark for the AIDS response and provides another example of the pathfinder role the response plays, particularly in demonstrating how reducing vulnerability and promoting human rights is critical to progress across health and sustainable development.

Putting the human rights tool into practice: Cuba at the front lines

Cuba, with its highly developed medical infrastructure and universal health-care, had reduced the rate of HIV transmission from mother-to-child to around 2% and eliminated congenital syphilis by 2012, following a concerted effort with the Pan American Health Organization (PAHO)/WHO. Cuba requested validation in late 2013, before the WHO guidelines had been finalized, becoming a pioneer for the process as a result. As Cuba's data quality, laboratory infrastructure and service provision are part of the country's well-established health system, the country easily met the validation criteria. However, the human rights criteria had not been fully clarified, requiring a collaborative effort to demonstrate that human rights were being protected in the

[6] Understanding and addressing human rights concerns in the context of the elimination of mother-to-child transmission of HIV and keeping mothers alive (eMTCT), including in the Global Plan. UNAIDS, 2012. http://www.emtct-iatt.org/wp-content/uploads/2014/08/Human-rights-and-eMTCT13Nov2012.pdf

context of the country's maternal and child health and HIV programmes.

Following consultations, UNAIDS was identified to lead the human rights component of Cuba's validation. UNAIDS worked with PAHO and representatives of women living with HIV to consolidate a user-friendly human rights, gender equality and community engagement checklist (see Box 2) as part of the human rights eMTCT tool. The checklist specified the considerations to be taken into account in the validation report submitted by countries at the start of the validation process. Cuba was the first country to be assessed with this checklist, by a UNAIDS-led team, and Cuban authorities expressed their interest in this component, taking it very seriously. They facilitated the assessment by providing access to legal and policy documents and enabling interviews with policy makers, service providers and numerous members of civil society including networks of women living with HIV. A strong, collaborative precedent was thus set through Cuba's validation, which was certified in 2015.

Box 2: Human rights, community engagement and gender equality checklist for validation of eMTCT

Countries applying for validation of eMTCT respect and comply with the human rights, community engagement and gender equality principles of:

1. Non-criminalization of mother-to-child transmission
2. No mandatory or coerced testing and treatment
3. Informed consent
4. No forced or coerced abortion, contraception or sterilization
5. Confidentiality and privacy
6. Equality and non-discrimination
7. Availability, accessibility, acceptability and quality of services
8. Accountability, and participation and community engagement
9. No gender-based violence
10. Access to justice, remedies and redress

Building on experience: UNAIDS' role in supporting validation of rights-based eMTCT

Drawing from Cuba's experience, UNAIDS has supported several other countries through successful validations, including Armenia, Belarus and Thailand, which were validated in June 2016. Working with UNICEF, UNFPA and WHO, countries assemble national validation reports, which are submitted to regional validation committees and eventually the Global Validation Advisory Committee (GVAC) for final assessment. Upon validation, WHO offers recommendations on how to maintain and continue to strengthen programmes, which should be implemented before reevaluation.

UNAIDS provides expertise on the human rights considerations for the national report—applying the human rights tool to gather evidence—and identifies gaps in the evidence provided. In addition, UNAIDS encourages countries to apply for validation and provides further impetus to meet the validation criteria. UNAIDS also facilitates the engagement of civil society in compiling the national report. For example, Raks Thai Foundation, the Women's Positive Network and many others were invited to participate in the human rights working group throughout the validation process in Thailand. UNAIDS enables civil society organizations, including networks of women living with HIV, to hold eMTCT stakeholders accountable in meeting the non-negotiable human rights standards.

At the regional level, UNAIDS ensures that at least one woman living with HIV and a human rights expert are included in the regional validation teams. As an observer of the regional validation committees and the GVAC, UNAIDS is well positioned to identify and effectively utilize opportunities to promote full implementation of human rights. UNAIDS strives to create space for civil society involvement at all of these stages, including by ensuring the representation of women living with HIV in the GVAC, and regional and country validation processes.

Ending AIDS also demands that efforts are made to raise the profile of eMTCT efforts and encourage their sustainability. UNAIDS took part in celebrating Cuba's elimination at a Washington, D.C. event and recognized Armenia, Belarus and Thailand's eliminations with the presentation of certificates of validation at the 2016 High-Level Meeting on Ending AIDS in New York. Ministers of Health received the certificates, and the events were extensively covered by international media, putting the spotlight on these countries' successes. The Prime Minister of Thailand was also presented with a certificate in another well-publicized ceremony in Bangkok. Events like these legitimize country approaches and raise awareness of HIV efforts more generally, reinforcing the drive to end all new HIV infections.

Safeguarding success and leveraging further gains

Being validated for eMTCT is not the end of the story. Complacency risks a rebound in new paediatric HIV infections. Therefore, while the non-negotiable criteria for elimination may have been met, key recommendations are made to countries to ensure the response is sustained. Countries will thus be reviewed every two years to ensure they have addressed the recommendations and that they are maintaining elimination. If not, their validated status could be revoked.

Cuba will be the first country to be reevaluated. Upon validation, several recommendations were made, including to consider closing the last remaining sanatorium institutionalizing people living with HIV and to ensure that the age-of-consent law is adopted to enable young people to access sexual and reproductive health services from the age of 14. Both recommendations are being implemented, demonstrating the potential of the validation exercise to continue to inspire positive change.

Other countries may confront greater challenges in maintaining validation if progress is not accelerated. In Thailand, access to HIV services within the universal health-care system, including those for prevention of mother-to-child transmission, has recently been extended to both documented and undocumented migrants, although uneven policy implementation has left gaps in service access for some. However, Thailand is firmly committed and is working to close all remaining gaps to ensure access for all Thai and non-Thai citizens. Thailand's experience confirms that once human rights concerns are recognized and acted upon, the situation can improve dramatically. For example, a study prior to the country's stigma reduction effort found about 20% of female respondents indicated that they were advised or pressured to terminate pregnancy based on being HIV positive. However, a more recent survey found that the number of pregnant positive women advised to consider abortion had dropped to 3%.

> *"Thailand has been working hard to eliminate mother-to-child transmission of HIV. The time has come when no child, Thai or non-Thai, shall be born with HIV. We are very proud that Thailand's achievement has been validated and recognized globally—and appreciate the partnership we have with WHO, UNICEF, UNAIDS and Thailand MOPH - US CDC collaboration."*
>
> Professor Piyasakol Sakolsatayadorn, Minister of Public Health, Thailand

In Armenia, overly broad criminalization of HIV transmission is a concern. Encouragingly, the government has expressed willingness to act on this issue, and work is progressing to amend the law. In Belarus, patient confidentiality and forced disclosure of HIV serostatus are cited in the validation recommendations, and the Belarus government has begun to address these.

Promising developments and broader applications

Although just a few countries are validated so far, many more are poised to follow. An estimated 85 countries have reached or are within reach of eliminating new HIV infections among children,[7] with some currently waiting for final confirmation from the GVAC. Caribbean countries are working in partnership with PAHO, UNICEF and UNAIDS to become the first region validated for eMTCT and syphilis by 2020, which would be a landmark achievement.[8]

A promising development is the South-South cooperation that has been fostered through the validation process. Thailand is now assisting other Member States of the Association of Southeast Asian Nations to strengthen prevention programmes and support preparations for validation. In the Caribbean, women living with HIV are being trained to take part in the regional validation teams.

Many countries with high HIV burdens have made rapid progress in reducing new HIV infections in children, such as Botswana and South Africa. UNAIDS has been involved in consultations on how best to recognize this progress without creating unrealistic expectations of imminent elimination. For example, the possibility of a 'pre-elimination' status is being explored, which would maintain the need for a human rights approach. Recognizing countries' progress can then inspire work towards full elimination of mother-to-child transmission of HIV as a public health challenge.

The emphasis on human rights, gender equality and community engagement in validating eMTCT has valuable lessons for other disease elimination programmes, and public health generally. The 2013-2016 Ebola outbreak saw stigmatization of and discrimination against sick people and health-care workers, due to a lack of information. Zika, mired with challenges relating to women's sexual and reproductive rights, is another case in point. UNAIDS is uniquely placed to provide leadership and lessons learned in responding to such challenges. With the launch of the new initiative, Start Free, Stay Free, AIDS Free, UNAIDS, PEPFAR and partners are building on the tremendous progress of the Global Plan. In the ongoing effort to eliminate new infections among children and keep their mothers alive, UNAIDS will remain at the front line, upholding and promoting human rights for all.

"It is important for countries to validate the elimination of HIV and to document their successes in stemming the HIV epidemic. Children must be protected by offering care, treatment and support, to their mothers in particular and also the affected family members. Validation of human rights is one of the important tools used and is absolutely necessary for achieving access to all needed services and helps to destigmatize persons living with HIV. Application of the tools has resulted in strengthening of health systems and programmes."

Dr Merceline Dahl-Regis, Co-Chair, Global Validation Advisory Committee

[7] On the Fast-Track to an AIDS-free generation. UNAIDS, 2016. http://www.unaids.org/sites/default/files/media_asset/GlobalPlan2016_en.pdf

[8] Elimination of Mother-to-Child Transmission of HIV and Syphilis in the Americas. Update 2015. PAHO, 2015. http://iris.paho.org/xmlui/bitstream/handle/123456789/18372/9789275118702_eng.pdf?sequence=3&isAllowed=y

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