UNAIDS 2019

Elimination without violation

Supporting women living with HIV in putting human rights at the centre of validating the elimination of mother-to-child transmission of HIV

Progress towards eliminating new HIV infections among children marks one of the greatest recent achievements in public health. Globally validating this 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.

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UNAIDS in Focus

TThe UNAIDS in Focus series features snapshots of the Joint Programme's work enabling people living with and affected by HIV around the world to realize their human right to health.

UNAIDS advocates for a holistic, multisectoral approach to AIDS, with a long history of working across sectors and building multistakeholder partnerships. As a joint programme, it uniquely leverages the capabilities and comparative advantages of each of its 11 United Nations (UN) cosponsoring organizations (Cosponsors), as well as those of civil society, governments and other partners.

This series of case studies captures compelling stories of how Cosponsors, the UNAIDS Secretariat and a wide range of partners join forces to overcome challenges and build solutions at the country, regional and global levels to address the needs and protect the rights of people living with, affected by and at risk of HIV. The case studies depict a wide array of interventions that make a difference, such as creating a coalition of lawyers to provide pro bono services to defend people living with HIV from discrimination, implementing a partnership in South-East Africa to ensure the continuity of health services for communities suffering from drought, or supporting countries in western and southern Africa to scale up prevention and treatment coverage in countries lagging most behind in their response.

By using evidence-informed and people-centred approaches, UNAIDS acts as an advocate, convenor and broker to address obstacles at the global, regional and country levels (including legal environments and social determinants) that are hindering access to essential, quality and sustainable care, treatment, support and prevention services. The UNAIDS in Focus series shows how the Joint Programme puts its mission into practice, delivering results for people everywhere in order to achieve zero new HIV infections, zero AIDS-related deaths and zero discrimination.

Summary

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. Globally, around 160 000 children aged 0–14 years became newly infected with HIV in 2018. This is a major decrease from 280 000 new infections in 2010 (UNAIDS, 2019), and a growing number of countries are closing in on the benchmark of eliminating the mother-to-child transmission of HIV. 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 eliminate the mother-to-child transmission of HIV, 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 eliminating the mother-to-child transmission of HIV.

In 2014, WHO, in partnership with UNAIDS, UNFPA and UNICEF, developed standardized criteria and global guidelines for validation *(1)*. Since human rights can be violated—especially women's sexual and reproductive rights—in the name of ending new HIV infections among children, UNAIDS has worked closely with the International Community of Women with Living with HIV and the Global Network of People Living with HIV (GNP+) to ensure that human rights, gender equality and community engagement considerations form a central aspect of validating the elimination of the mother-to-child transmission of HIV. This marks the first time in public health history that protecting human rights has been considered a prerequisite to validating disease elimination.

Towards an AIDS-free generation

In 2011, when almost no children born to HIV-positive mothers were living with HIV in high-income countries, more than 250,000 acquired HIV in poorer countries. To address this injustice, UNAIDS and the United States President's Emergency Plan for AIDS Relief (PEPFAR) launched a special partnership to catalyse action for the health and survival of both mothers and babies. With support from other partners, including WHO, UNICEF, governments, 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 frontline communities, and stimulated innovative approaches and 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. It successfully built political momentum and set bold targets enabling accountability.

Together with the United States President's Emergency Plan for AIDS Relief (PEPFAR), UNAIDS launched the Start Free Stay Free AIDS Free framework in 2016 to build on the achievements of the Global Plan. The Start Free Stay Free AIDS Free framework promotes a set of human rights-based interventions to end AIDS as a public health threat among children and adolescents. It focuses on enhancing actions in 23 countries with high numbers of children, adolescents and young women living with HIV. In 2018, these countries together accounted for globally, 86% of pregnant women living with HIV; 80% of children aged 0–14 years acquiring HIV; 85% of adolescent girls and young women aged 10–24 years acquiring HIV; and 85% of children and adolescents aged 0–19 years living with HIV *(2)*.

Recognizing the rights at stake

The 2014 WHO guidelines for validating the elimination of the mother-to-child transmission of HIV lay out specific thresholds for achieving elimination, including the number of children acquiring HIV per 100,000 births and the levels of service coverage. As current HIV prevention, diagnosis and treatment services for pregnant and breastfeeding women are not 100% effective in preventing mother-to-child HIV transmission, fully eradicating HIV among children is not currently feasible. WHO has therefore defined "elimination" as reducing the number of children acquiring HIV to a level low enough that it no longer constitutes a public health problem[1] *(3)*.

This approach was also adopted for congenital syphilis, for which mother-to-child transmission can be prevented through simple, low-cost screening and treatment of pregnant women. Since 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.

The status of validation, however, could not simply be granted based on the rate of transmission of HIV from mother to child.

Networks of women living with HIV have long identified human rights violations in maternal and child health-care settings. Around the world, when women access HIV services, they report facing stigma, discrimination and even physical violence (Box 1). Discrimination against women living with HIV within health-care settings often results in the inability to access care, poor quality services 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 several countries, HIV-specific laws or existing criminal law provisions could be applied to prosecute HIV exposure or transmission during pregnancy, delivery or breastfeeding *(4, 5)*.

[1] To qualify for validation, countries must demonstrate that the mother-to-child transmission of HIV was eliminated without violating HIV-related human rights, gender equality and community engagement principles. The human rights tool also enables countries applying for validation to review whether their programmes for eliminating the mother-to-child transmission of HIV are addressing these issues. It provides a pragmatic approach to assessing and upholding human rights and is continually being strengthened. See reference 4.

Box 1.

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

- In a study across Burkina Faso, Kenya, Malawi and Uganda, 1 in 10 adults living with HIV had experienced discrimination in health-care facilities.[a]
- The People Living with HIV Stigma Index documented that for women living with HIV:

  40% reported being advised against having a child 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).[b]

[a] Neuman M, Obermeyer CM,MATCH Study Group. Experiences of stigma, discrimination, care and support among people living with HIV: a four country study. AIDS Behav. 2013;17:1796–1808.

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

WHO and UNAIDS have long defended that action 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 realize all human rights, including the right to health, free non-discrimination; the right to establish a family; and the right to information, confidentiality, expression, privacy, association and participation.

WHO and UNAIDS therefore turned to civil society to jointly design rights-related validation criteria. UNAIDS supported the International Community of Women with Living with HIV and GNP+ in developing a tool for assessing whether the mother-to-child transmission of HIV was eliminated in a manner respectful of human rights. The tool is an integral part of the validation process, used for independently assessing 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.

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

Cuba at the frontline

Cuba, with its highly developed health-care infrastructure and universal health coverage, had reduced the rate of HIV transmission from mother to child to about 2% and eliminated congenital syphilis by 2012, following a concerted effort with the Pan American Health Organization (PAHO) *(6)*. Cuba requested validation of status of elimination in late 2013, before the WHO guidelines had been finalized, becoming a pioneer for the process as a result. Since 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 context of the country's maternal and child health and HIV programmes.

UNAIDS led the human rights component of Cuba's validation and worked with PAHO and representatives of women living with HIV to consolidate a user-friendly checklist for human rights, gender equality and community engagement (see Box 2) as part of the human rights tool for eliminating the mother-to-child transmission of HIV. The checklist specified the factors to be considered in the validation report submitted by countries. 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. They facilitated the assessment by providing access to legal and policy documents and enabling interviews with policymakers, 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 validating the elimination of the mother-to-child transmission of HIV

Countries that apply for validation of their status to eliminate mother-to-child transmission of HIV 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 the validation process

Drawing from Cuba's experience, UNAIDS supported several other countries towards successful validation, including Armenia, Belarus, Moldova and Thailand, which were validated in June 2016. Seven territories were validated in 2017 and Malaysia in October 2018. Working with UNICEF, UNFPA and WHO, countries assembled national validation reports, which were submitted to regional validation committees and eventually the Global Validation Advisory Committee (GVAC) for final assessment. Upon validation, GVAC could also offer recommendations on how to maintain and continue to strengthen programmes, which should be implemented before re-evaluation *(7)*.

UNAIDS has been encouraging countries to apply for validation and when they do, has provided expertise on the human rights requirements needed for the national validation report—applying the human rights tool to gather evidence and identifying gaps in the evidence provided. UNAIDS also facilitated engagement of civil society in compiling national reports. For example, the 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 enabled civil society organizations, including networks of women living with HIV, to hold stakeholders in this process 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 Global Validation Advisory Committee, UNAIDS is well positioned to identify and effectively use opportunities to promote the full implementation of human rights. UNAIDS strives to create space for civil society involvement at all stages, including by ensuring the representation of women living with HIV in the Global Validation Advisory Committee and regional and country validation processes.

Putting the spotlight on these countries' successes, UNAIDS presented the Health ministers of Armenia, Belarus, the Republic of Moldova and Thailand with certificates of validation of status of elimination at the 2016 High-Level Meeting on Ending AIDS in New York.

Safeguarding success and leveraging further gains

The validation of status of elimination of mother-to-child transmission of HIV is not the end of the story. Post-validation complacency could lead to a rebound in the number of children acquiring HIV. Therefore, although the non-negotiable criteria for elimination have been met, key recommendations are made to countries to ensure that the progress is sustained. Countries will thus be reviewed every two years to ensure that they have addressed the recommendations and that they are maintaining the status of elimination. If not, their validated status could be revoked.

Cuba was the first country to be re-evaluated. In 2015, Cuba received several recommendations upon validation, including considering closing the last remaining sanatorium institutionalizing people living with HIV and ensuring 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.

In South-East Asia, HIV prevalence among migrants from neighbouring countries to Thailand used to be up to four times the rate of HIV prevalence found among the general population *(8)*. In the context of universal health coverage, Thailand has extended the provision of HIV services to documented and undocumented migrants. The government now provides all pregnant migrant women with free antenatal care and prevention of mother-to-child transmission services and provided health insurance for 1.45 million migrants in 2015 *(9)*. Thailand's experience confirms that, once human rights concerns are recognized and acted upon, the situation can improve dramatically.

In Armenia, the recommendations pointed to overly broad criminalisation of HIV transmission. The Government recognised the concern and is proactively progressing to amend the law. In Belarus, the validation recommendations cite patient confidentiality and forced disclosure of HIV-status, and the Belarus government has begun to address these issues. Today, HIV tests offered in prisons are confidential and testing accompanied by confidential pre- and post- testing counselling. However, more effort is needed to address the laws that criminalize transmission of, non-disclosure of or exposure to HIV transmission.

Promising developments and broader application

Although just a few countries have been validated so far, many more are poised to follow. Caribbean countries are working in partnership with PAHO, UNICEF and UNAIDS to become the first region validated for eliminating the mother-to-child transmission of HIV and syphilis by 2020, which would be a landmark achievement *(10)*.

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 a high burden of HIV infection, such as Botswana and South Africa, have made rapid progress in reducing the number of children acquiring HIV. WHO is leading discussions on how best to recognize this progress without creating unrealistic expectations of imminent elimination. A "pathway to elimination" status is being explored, which would maintain the need for a human rights approach. Recognizing countries' progress can then inspire work towards fully eliminating the mother-to-child transmission of HIV as a public health challenge.

The emphasis on human rights, gender equality and community engagement in validating the elimination of the mother-to-child transmission of HIV has valuable lessons for other disease elimination programmes and for public health generally. In the 2013-1016 Ebola outbreak, sick people and health-care workers were stigmatized and discriminated against because of lack of information. The zika outbreak, mired with challenges relating to women's sexual and reproductive rights, is another example. UNAIDS is uniquely placed to provide leadership and lessons learned in responding to such challenges.

Recent data from UNAIDS global report 'Communities at the centre' show that there is no space for complacency, as progress for children has slowed. Although the scaling-up of antiretroviral therapy for pregnant women living with HIV, with 82% [62–95%] of them receiving antiretroviral medicines in 2018, has driven progress towards the elimination of mother-to-child transmission, an unacceptable 160 000 [110 000–260 000] children (0–14 years) globally acquired HIV in 2018. We are far away from the target of fewer than 40 000 by the end of 2018, and the 2020 target of a 95% reduction in new HIV infections among children is in danger of being missed. Weak health systems are holding back progress, as are competing national priorities and shifts in donor funding.

Focused investments are needed to strengthen a cascade of services for eliminating child infections. The most effective way to prevent children from acquiring HIV is to ensure women are empowered to protect themselves from acquiring the virus. Primary prevention, treatment and retention in care are also paramount, but are still a major shortfall in the global AIDS response.

In the ongoing effort to eliminate new infections among children and keep their mothers alive, UNAIDS will remain at the frontline, upholding and promoting human rights for all.

References

1. Global guidance on Criteria and processes for validation: Elimination of Mother-to-child Transmission of Hiv and syphilis Second edition, 2017, WHO.

2. Start Free, Stay Free, AIDS Free, UNAIDS, 2019. https://www.unaids.org/sites/default/files/media_asset/20190722_UNAIDS_SFSFAF_2019_en.pdf.

3. Global guidance on criteria and processes for validation: elimination of mother-to-child transmission of HIV and syphilis. Geneva: World Health Organization; 2014.

4. Vertical HIV transmission should be excluded from criminal prosecution. Csete J, Pearshouse R, Symington A. Reprod Health Matters. 2009;17:154–62.

5. HIV-specific legislation in sub-Saharan Africa: a comprehensive human rights analysis. Eba PM. Afr Hum Rights Law J. 2015;15;224–62.

6. The Cuban Experience in the Elimination of Mother-to-Child Transmission of Congenital Syphilis; Rodriguez I, Noda AA, Ale K, Stamm LV; Am J Public Health, 2016, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5055795/.

7. Elimination of mother-to-child transmission of HIV and syphilis in the Americas, Pan American Health Organization: Washington, DC. 2016. http://iris.paho.org/xmlui/bitstream/handle/123456789/34072/9789275119556-eng.pdf

8. The Gap Report, UNAIDS: Geneva. 2014. https://www.unaids.org/sites/default/files/media_asset/UNAIDS_Gap_report_en.pdf.

9. Thailand eliminates mother-to-child transmission of HIV and syphilis. Sidibé, M., & Singh, P. K. (2016). The Lancet. https://doi.org/10.1016/S0140-6736(16)30787-5.

10. Elimination of mother-to-child transmission of HIV and syphilis in the Americas. Update 2015. Washington (DC): Pan American Health Organization; 2015.

UNAIDS
Joint United Nations
Programme on HIV/AIDS

20 Avenue Appia
1211 Geneva 27
Switzerland

+41 22 791 3666

unaids.org