

# CHILDREN AND PREGNANT WOMEN LIVING WITH HIV



HIV is the leading cause of death among women of reproductive age. In 2013, 54% of pregnant women in low- and middle-income countries did not receive an HIV test, a key step to accessing HIV prevention, treatment and care (1). Without treatment, about one third of children living with HIV die by their first birthday and half die by their second. For children, the health benefits of HIV treatment are magnified. Beginning antiretroviral therapy before the twelfth week of life reduces HIV-related mortality in children living with HIV by 75% (2).

# { CHILDREN AND PREGNANT WOMEN LIVING WITH HIV

## I am a pregnant woman living with HIV. I face these issues.



# I am a child living with HIV. I face these issues.

I get sick often,  
but my mother  
has no money  
to pay for the  
clinic

My parents both  
died of AIDS and  
I live with my  
grandmother

I am scared  
that I will die  
because my  
baby sister died

Other children  
will not play with  
me in school,  
because they  
know I have HIV

My HIV treatment  
stopped when my  
family moved to a  
different village

The school does  
not teach us about  
our bodies or  
sexual health

People whisper  
that I have  
something bad,  
but I do not  
understand

I have dropped  
out of school,  
because I am  
often sick

I worry about  
my mother  
because she  
gets ill often



# WHY CHILDREN AND PREGNANT WOMEN LIVING WITH HIV ARE BEING LEFT BEHIND

HIV is the leading cause of death among women of reproductive age. In 2013, 54% of pregnant women in low- and middle-income countries did not receive an HIV test, a key step to accessing HIV prevention, treatment and care (1). Without treatment, about one third of children living with HIV die by their first birthday and half die by their second. For children, the health benefits of HIV treatment are magnified. Beginning antiretroviral therapy before the twelfth week of life reduces HIV-related mortality in children living with HIV by 75% (2).

## HIV BURDEN

Of the 3.2 million children living with HIV, 91% live in sub-Saharan Africa, 6% live in Asia and the Pacific and the remaining 3% are situated in the rest of the world (3).

*In 2013, an estimated 1.5 million women living with HIV gave birth, virtually unchanged from 2009.*

*Globally, 3.2 million children under 15 were living with HIV in 2013, comprising 9.1% of all people living with HIV.*

*240 000 children worldwide acquired HIV in 2013: one new infection every two minutes.*

## The Top 4 Reasons

# 01

Limited access to sexual and reproductive health and HIV services

# 02

Limited access to HIV treatment

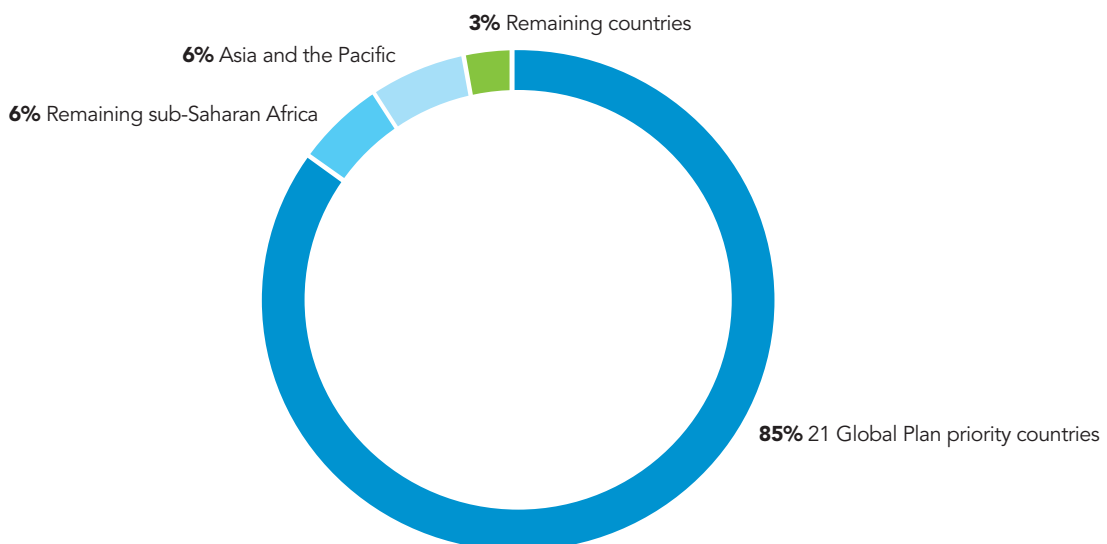
# 03

Failure to prioritize children

# 04

Poorly integrated health-care services

## Children (aged 0–14 years) living with HIV, globally



Source: UNAIDS 2013 estimates.

Launched in 2011, the Global Plan towards the elimination of new child HIV infections and keeping their mothers alive has focused efforts on priority countries (4), 21 of which are in sub-Saharan Africa, where 85% of pregnant women living with HIV reside.<sup>1</sup>

While progress has been made in these priority countries, much more effort is needed to reach the Global Plan’s target of reducing new infections among children by 90% by 2015. In 2013, 1.3 million [1.2 million–1.4 million] women living with HIV gave birth—a figure which is unchanged from 2009. However, the number of children newly infected fell from 350 000 in 2009 to 199 000 [170 000–230 000] in 2013. The rate of mother-to-child transmission also fell—in 2013, 16% [13–18%] of children born to women living with HIV became infected compared to 25.8% in 2009.

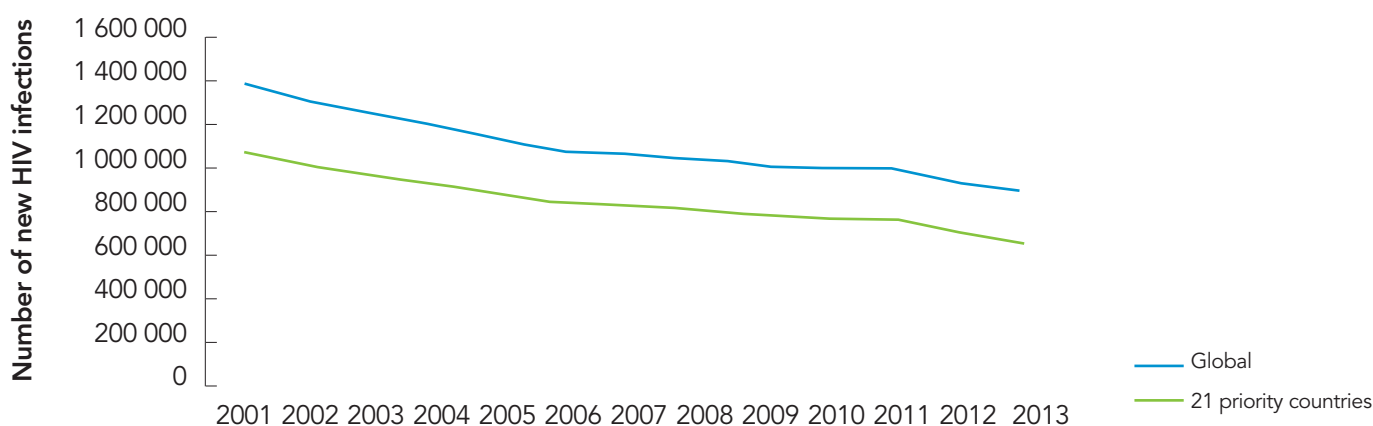
HIV testing among pregnant women remains challenging. Globally, about 44% of pregnant women in low- and middle-income countries received HIV testing and counselling in 2013, up from 26% in 2009 (1).

### Limited access to sexual and reproductive health and HIV services

Many women living with HIV continue to lack access to HIV prevention, treatment, care and support services and sexual and reproductive health services. Children also continue to become infected perinatally—that is, in utero, during labour or while breastfeeding.

Progress in stopping new infections among children and ensuring that mothers are alive and healthy requires reaching the full cross-section of pregnant women with essential health services.

### Number of new HIV infections among reproductive-age women (15–49 years old) globally and in 21 priority countries, 2001–2012



Source: UNAIDS estimates, 2013.

<sup>1</sup> There are 22 Global Plan countries, and 21 of these are in sub-Saharan Africa. They are: Angola, Botswana, Burundi, Cameroon, Chad, Côte d’Ivoire, the Democratic Republic of the Congo, Ethiopia, Ghana, Kenya, Lesotho, Malawi, Mozambique, Namibia, Nigeria, South Africa, Swaziland, Uganda, the United Republic of Tanzania, Zambia and Zimbabwe. The 22nd country is India.

## Services to help pregnant women remain HIV-free

In virtually every country, the majority of pregnant women who receive an HIV test are HIV-negative. Programmes focus attention on women who test positive for HIV, with an understandable desire to initiate treatment and care. However, equal attention is needed to help HIV-negative pregnant women who are already in contact with the health-care system prevent infection.

There are currently few interventions being implemented to help women to remain HIV-free during pregnancy, breastfeeding and beyond. More effort is needed to address this gap. It may be particularly important for adolescent women, who may have less experience with and information about HIV.

## Services to ensure reproductive rights and prevent unintended pregnancies

Women, including women living with HIV, should have a right to have the number of children they want and to space them to suit their own life's circumstances. For this reason, family planning remains one of the four pillars of guidance on the prevention of the vertical transmission of HIV.

Reducing the number of unintended pregnancies among women living with HIV would not only reduce the number of children acquiring HIV but would also improve the lives of women and children. This is crucial for adolescent women, who are at greater risk for pregnancy-related complications. Spacing pregnancies is also beneficial to the health of a woman living with HIV infection.

A mathematical projection from 2009 on the burden of paediatric HIV in Uganda indicated the synergistic effect of family planning on reducing the number of HIV-positive pregnancies. The model showed that, while HIV services to prevent mother-to-child transmission averted an estimated 8.1% of vertical infections, family planning averted 19.7%. According to the model, unintended pregnancies accounted for 21.3% of new paediatric infections (5).

A recent systematic review of family planning uptake indicates that services that provided more immediate access to a wider range of contraception produced somewhat better results than those that offered referral or access to a reduced range of family planning methods (6). This includes recognizing the reproductive rights of women living with HIV, allowing them to make informed choices regarding their childbearing desires and to access sexual and reproductive health services.

Expanding access to contraception has also been shown to be a particularly cost-effective investment: a recent analysis published in *The Lancet* demonstrated that family planning would potentially account for half of all deaths prevented from among several interventions examined (7). If all women wanting to avoid pregnancy used modern family planning methods, unintended pregnancies would decline by 71%. At present, providing health care related to unintended pregnancies costs about US\$ 5.7 billion annually (8).

## HIV testing and counselling services for pregnant women

Access to treatment begins with access to counselling and testing. Despite global efforts, only 44% of pregnant women in low- and middle-income countries received HIV testing and counselling in 2013, with even fewer receiving testing services with their male partners.

Pregnant women who test negative during pregnancy should also be offered opportunities to retest in order to identify seroconversion during pregnancy or during breastfeeding. Community- and home-based testing efforts can be useful in reducing the financial, social and opportunity costs that women may incur if they have to go to the facility for the test. All HIV counselling and testing should be provided confidentially and voluntarily.

## Access to health care for the poorest women

An analysis by the United Nations Children's Fund (UNICEF) shows pronounced inequities in coverage for many essential health services, whereby pregnant women from wealthier households are more likely to receive care than those from poorer households (9).

This pattern is particularly evident for services that require a functional health system, which includes personnel such as skilled birth attendants. Consequently, women in the poorest quintile are two to three times less likely than those in the richest households to have access to or use these vital interventions. Data show that countries achieving rapid progress in the coverage of essential interventions have accomplished this primarily by improving coverage among the poorest wealth quintiles. This is, in part, due to the recognition that these populations have the greatest potential for gains.

Pregnant women who are poor, the most deprived, achieve low levels of education, live in rural areas and are more likely to lack access to services than other women, many of whom are adolescent women. Efforts must concentrate on addressing the HIV needs of the poorest—and other vulnerable groups of—pregnant women in the population.

Therefore, programme advisers are now recommending that countries decentralize services to the lowest levels and include equitable considerations in order to target vulnerable women when developing strategies for scaling up interventions (9,10).

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**Progress in stopping new infections among children and ensuring that mothers are alive and healthy requires reaching the full cross-section of pregnant women with essential health services.**

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## Limited access to antiretroviral medicines

To improve the health outcomes of women and children, improvements in accessing HIV treatment as well as adherence to therapy are needed.

As of 2013, all pregnant women living with HIV are eligible for treatment. Although solid progress has been made in providing services to prevent vertical transmission, three out of ten pregnant women living with HIV in 2013 still did not receive effective antiretroviral medicines to prevent the transmission of HIV to their children.

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## Paediatric medicines

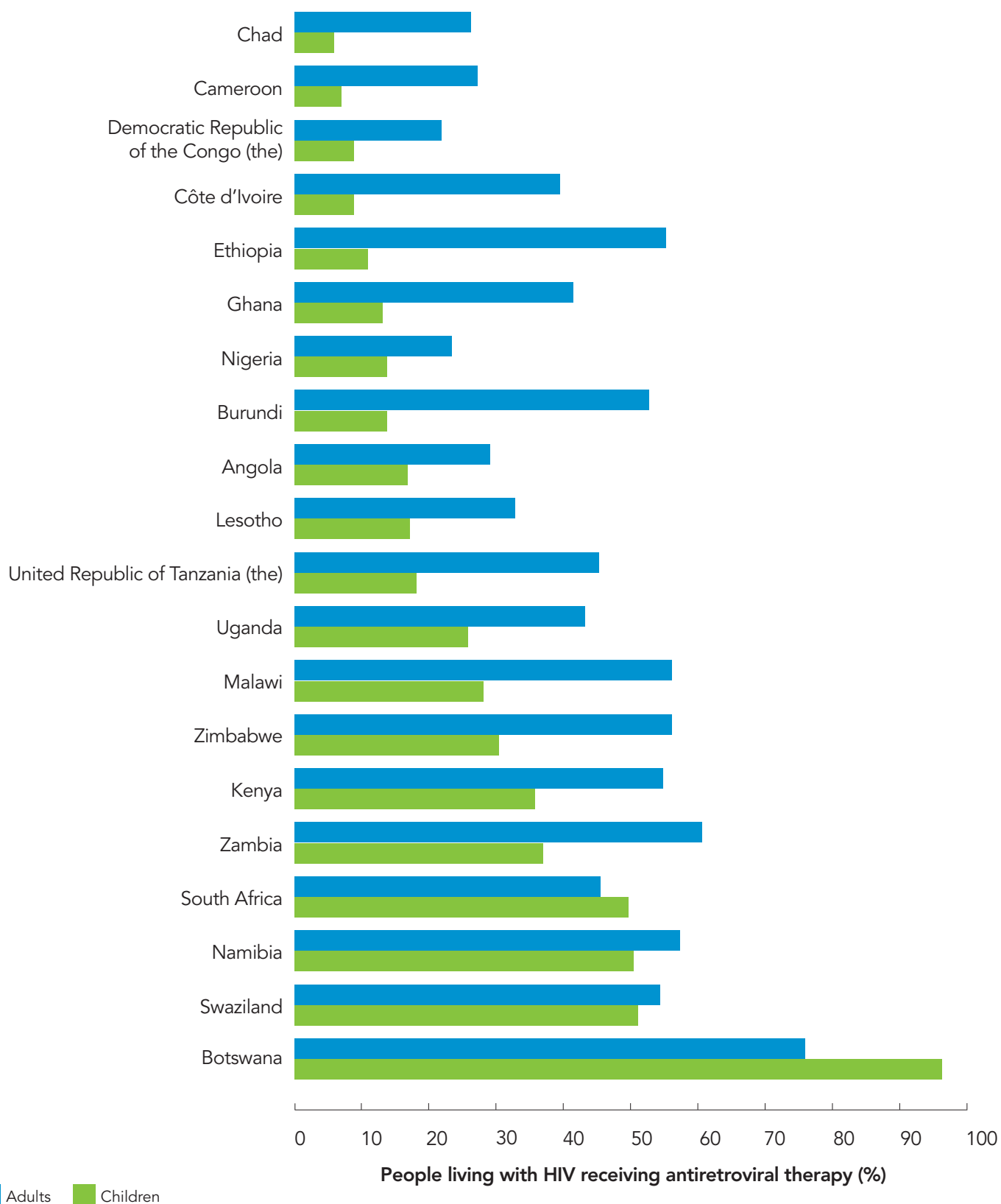
There are fewer antiretroviral drugs available for use by children and children incur higher treatment costs. Children living with HIV are one third less likely to receive antiretroviral therapy compared to adults. Treatment can only be successful if children receive and are assisted to adhere to their medication, but often this is not the case. Results from a study of 11 sites in Cameroon showed that only 32% of infants with a positive HIV test result were alive and on treatment 18 months later (11).

There is also a need for countries to reprioritize co-trimoxazole prophylaxis in paediatric HIV treatment, as recommended by the World Health Organization (WHO) since 2006. Expanding access to co-trimoxazole prophylaxis requires a set of interrelated interventions, including strengthening links between HIV testing and treatment and establishing mechanisms to identify and follow up HIV-exposed infants.

Medication supply issues further hamper paediatric treatment. Complex formulas complicate pricing and ordering decisions and are contrary to a public health approach that focuses on the uptake of a limited number of optimized regimens.



Percentage of adults (aged 15+) and children (aged 0–14) living with HIV who were receiving antiretroviral therapy in 2013, in 21 priority countries



Source: 2013 estimates from UNAIDS, WHO and UNICEF.

## Failure to prioritize children

Without treatment, about one third of children living with HIV die by their first birthday and half die by their second birthday. Initiating antiretroviral therapy before the twelfth week of life reduces HIV-related mortality in children living with HIV by 75% (2).

HIV-exposed infants should be tested using a specialized virological test. Yet, in 2013, only 42% of infants born to mothers living with HIV in low- and middle-income countries received this test within two months as recommended by WHO (1,12). While this is appreciable progress considering the recommendations were released in 2010, 58% of children were still missed.

There are often limited laboratories and clinics available that meet paediatric care needs. By making children a higher priority, sites offering adult treatment could achieve the capacity to provide paediatric diagnoses and treatment as well.

Provider-initiated paediatric testing in locations where children living with HIV might be found can expand efforts to identify eligible children. Data from four facilities in Uganda showed a 50% increase five months following the scaling up of infant diagnosis among HIV-exposed babies tested each month, a 19% increase in the proportion of those tested receiving results and a younger age at infant diagnosis (13).

In addition, many children do not receive their conclusive HIV test at the end of breastfeeding when the risk of vertical transmission ends—a lost opportunity to link those who may have seroconverted into care. Programmes are now strengthening their efforts to ensure that HIV-exposed children receive a final diagnosis once breastfeeding ends.

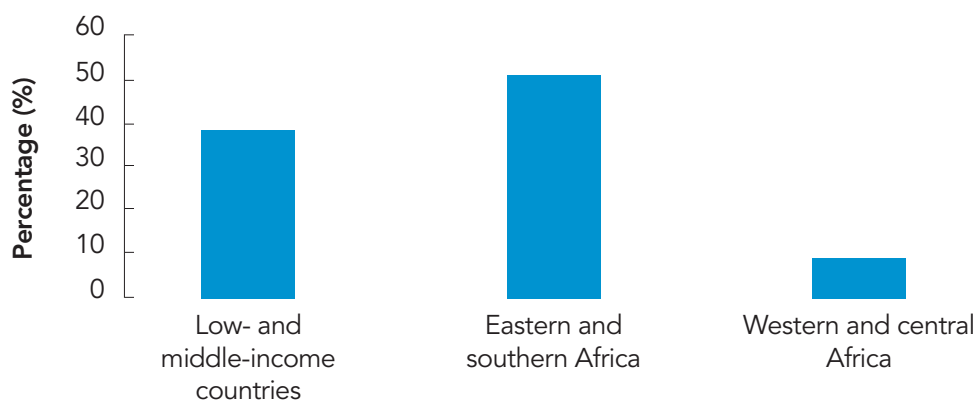
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**By making children a higher priority, sites offering adult treatment could achieve the capacity to provide paediatric diagnoses and treatment as well.**

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## Percentage of children born to HIV-positive women tested for HIV within two months of birth by region



Source: Global AIDS Response Progress Reporting 2013.

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In 2012, only 30% of children who were tested were referred for initiation of antiretroviral therapy (14). Given the rapid mortality associated with paediatric HIV infection, this slow action intuitively condemns many children to ill health and death.

## Need for disaggregated data on children

To be effective, programmes need accurate data. At the moment, the data being collected on children are not providing a clear enough picture to enable programme planners to assess and respond fully to children's needs.

At a minimum, the numbers of children tested and on treatment should be disaggregated and monitored using the following age groups: under <1 year, 1–4 years, 5–9 years, 10–14 years and 15–19 years. This disaggregation can enable greater attention to the specific gaps that need to be addressed for children and adolescents.

Disaggregation by sex and risk factors are particularly important in adolescents—those aged 10–19 years.

More broadly, disaggregated data is needed for men and women, especially in order to identify inequities and vulnerabilities. Analysing data by wealth quintiles, for example, can help assess which factors exclude key subpopulations of women and children in order to design equitable and effective solutions.

## Poorly integrated health care

There are great opportunities for better-coordinated care which takes into account the health and well-being of the whole person. Broader health service integration that is family-centred, covering maternal and child health, sexual and reproductive health and HIV services, would help to ensure that women and children receive the care they need when they need it.

Service delivery integration shows promise in improving various outcomes, with existing examples of promising models of integration (15). A Zambian study demonstrated a doubling in the proportion of treatment-eligible pregnant women starting antiretroviral therapy prior to delivery through an integrated HIV treatment and antenatal care strategy compared to those simply referred to an antiretroviral therapy clinic (16). Another study carried out in a clinical research setting demonstrated the effectiveness of integrating family planning into HIV services through a higher uptake of contraception and a decrease in pregnancy rates (17).

## Family-centred care including positive male involvement

Because HIV affects the family, it helps to manage it within a family context. Through couples' testing and counselling services, couples can learn their results together with the assistance of a trained counsellor or health worker. Unfortunately, such services are not always available.

An HIV-positive diagnosis for a pregnant woman can be an opportunity for a health-care provider to facilitate family conversations and to reach the whole family, to identify other HIV-positive children and to ensure that they are linked to life-saving care. This may be especially important for adolescents, who may have been missed during perinatal diagnoses and whose HIV infection may progress slowly.

The role of men is particularly important. A prospective cohort study in Kenya showed significantly lower rates of vertical HIV transmission among the infants of women whose male partners accompanied them to antenatal clinics or who reported that their male partners had been tested for HIV. Adjusting for maternal viral load, the combined risk for either vertical transmission or mortality was 45% lower with male antenatal attendance and 41% lower with previous partner testing (18). The involvement of male partners also provides an opportunity to identify discordant couples and, therefore, facilitate access to treatment.

Family-centred care will require age-sensitive disclosure. Non-disclosure of a pregnant woman's HIV status to her partner has been associated with the suboptimal prevention of mother-to-child transmission and poor treatment adherence (19). Non-disclosure to adolescents can lead to fear and frustration during this vulnerable and turbulent age period. Disclosure can help increase the uptake of HIV testing and other services, and can enable a supportive and cohesive family environment. It, however, needs to be voluntary, sensitive and address the risks of negative consequences.

## Community involvement, outreach and treatment literacy

Services also need to go beyond the health centre into the community. Psychosocial peer support has been shown to improve services aimed at preventing HIV transmission from mothers to their children. An evaluation of mothers to mothers (m2m), a clinic-based support initiative that employs HIV-positive mothers as peer educators, revealed that those participating in the m2m programme were significantly more likely to:

- Disclose their HIV status to at least one person.
- Receive CD4 cell count testing during pregnancy.
- Receive antiretroviral drugs for themselves and their infants.

- Practice an exclusive method of infant feeding.

Treatment literacy is particularly essential for paediatric diagnosis, treatment and disease management. In addition, women need accurate information about their own use of antiretroviral drugs. Misunderstandings about treatment have been linked to poor adherence and loss to follow-up, increasing the chances of drug resistance and treatment failure (20).

Caregivers who support children may delay care if they fail to recognize symptoms, are unaware of where to receive care and if they live in the context of a stigmatizing and misinformed community. Poor treatment literacy may also foster a passive environment, where caregivers may be unaware of their rights—and obligations—to quality services.

## Ensuring service provision respects human rights

Protecting human rights is essential to ensuring that women living with HIV come forward to access HIV-related services in order to avoid the risk of vertical transmission to their children and to receive and adhere to the treatment that they need for their own health.

A broad range of human rights concerns have been documented in the context of HIV services for pregnant women and children (21–25). They include the experiences of stigma, neglect and other negative attitudes and behaviours towards pregnant women living with HIV in health-care facilities (21,24). People have been subjected to mandatory or a lack of informed consent to HIV testing and/or treatment, a lack of confidentiality or insufficient information and counselling on HIV testing and treatment (23). The involuntary sterilization of women living with HIV, forced abortions and the criminalization of the vertical transmission of HIV have all been reported (22).

There are also concerns over a lack of sensitivity in programmes towards the needs of women living with HIV who are also marginalized because they are, for example, poor, young, disabled, sex workers or drug users.

In recent years, increased advocacy and actions by women living with HIV and others are yielding results. In 2013, the African Commission on Human and Peoples' Rights adopted a resolution that expressly condemns involuntary sterilization as a human rights violation and called on African States to adopt measures to prevent and address it (26).

In June 2014, WHO, UNAIDS, OHCHR, UN Women, UNDP, UNICEF and UNFPA adopted an interagency statement on eliminating forced, coercive and otherwise involuntary sterilization, which calls for an end to the involuntary sterilization of women living with HIV (27). Addressing human rights concerns and violations in the context of eliminating mother-to-child HIV transmission requires a number of concrete actions at the country and community levels (28,29).

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**Broader health service integration that is family-centred, covering maternal and child health, sexual and reproductive health and HIV services, would help to ensure that women and children receive the care they need when they need it.**

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# CLOSING THE GAP

We will continue to fail many children and pregnant women unless efforts are redoubled to overcome the obstacles which bar their access to life-saving HIV services, including testing, prevention, treatment, care and support.

Business as usual will only take us to a 65% reduction in new HIV infections among children between 2009 and 2015, instead of the target of 90% that countries aspire to reach.

Meeting global targets for antiretroviral therapy access among children and pregnant women living with HIV will require the equitable expansion of services along the entire maternal and child health continuum at primary-level facilities and strengthening health systems including antenatal and postnatal services as well as in the sphere of labour and delivery. It will also require the integration of HIV services—including chronic care management—for women, children and others in the family as well as in the broader community.

It will also require strengthening links to other key services, such as nutritional counselling, to support safe breastfeeding based on personal preferences and circumstances.

The community and private sectors, in collaboration with governments, have the potential to address the long-standing gaps among the hardest to reach. Such programmes are likely to be challenging; but, as AIDS activism has shown, a social justice focus can catalyse the most lasting benefits.

## HOW TO CLOSE THE GAP

# 01

Improve access to health and HIV services for all women and children

# 02

Ensure treatment is available for all in need

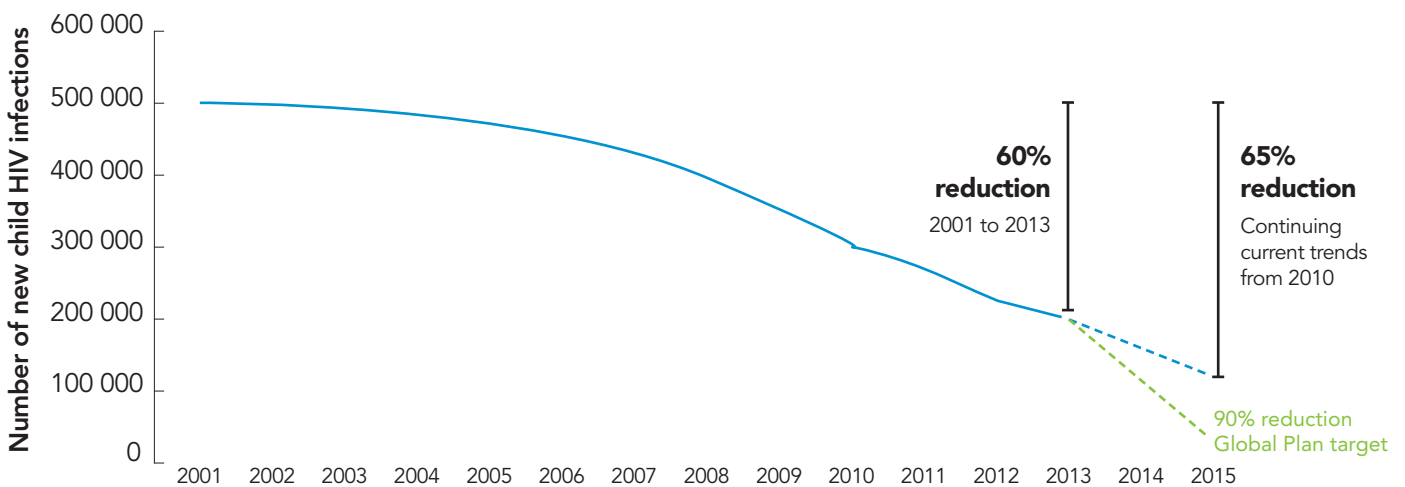
# 03

Invest in paediatric commodities and approaches

# 04

Scale up integrated, family-centred health care services and information

## Number of new child HIV infections globally, 2005–2013, and projected targets



Source: UNAIDS 2013 estimates.

A number of actions can accelerate progress.

#### **For both children and pregnant women living with HIV:**

- Adopt the 2013 WHO guidelines on antiretroviral therapy and improving service delivery.
- Integrate maternal and child health and paediatric HIV treatment and other care services, so that a woman and her child can receive care from the same provider during a single visit.
- Reduce the key barriers to utilizing and accessing services, such as distance to the clinic, out-of-pocket costs, waiting times and poor treatment by health-care providers.
- End stigma and discrimination.
- Promote family-centred care, including male involvement where the woman desires it.
- Improve health service delivery by strengthening human resources, creating mentoring systems, maximizing the capacity of community health workers and optimizing task shifting.
- Decentralize health services and scale up actions to reach the poorest households, who often live in remote areas or urban slums and disproportionately comprise ethnic minorities.
- Foster grassroots innovative approaches in order to reach isolated and marginalized groups and bring them much-needed programmes and services.
- Train health-care workers on non-discrimination, confidentiality, informed consent and other human rights and ethical principles.
- Monitor and evaluate human rights issues to ensure that they are documented and addressed.
- Reform laws, policies and practices that negatively impact human rights.
- Empower women living with HIV to know their rights and inform decision-making through legal literacy and information on patient rights and legal services programmes.
- Strengthen community and peer support especially through other women living with HIV.
- Meaningfully engage women living with HIV, human rights groups and women's organizations in the development and implementation of HIV programmes, including through technical and financial support.

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- Engage community-based organizations, including networks of women living with HIV, to support patients and health-care workers in improving the access to and uptake, quality and effectiveness of HIV services.

**Actions to address the gaps in meeting the HIV service needs of pregnant women living with HIV include:**

- Improving access to voluntary counselling and testing.
- Ensuring that voluntary couples counselling and testing is available.
- Ensuring that all HIV services are voluntary, confidential and of high quality, including referrals and follow-up.
- Ensuring that women living with HIV have full and complete information and an understanding of their sexual and reproductive health options, risks and benefits and the ability to choose freely among them.
- Providing lifelong treatment for all pregnant women according to the 2013 WHO guidelines (12) to prevent vertical transmission while at the same time safeguarding the woman's health.
- Providing treatment to the remaining 30% of pregnant women living with HIV who are not receiving antiretroviral therapy to prevent vertical transmission.
- Paying extra attention to pregnant adolescents.

**The interventions that are needed in order to better support children living with HIV include:**

- Improving early infant diagnosis by identifying HIV-exposed infants and ensuring that all HIV-exposed children receive a final diagnosis once breastfeeding ends.
- Increasing the number of sites and providers who can provide testing and treatment for children.
- Strengthening the supply chain of paediatric commodities including drugs and diagnostics.
- Promptly treating all children younger than 5 years of age immediately once a positive HIV test is confirmed.
- Expanding access to co-trimoxazole prophylaxis in paediatric HIV treatment, as recommended by WHO since 2006.
- Strengthening the continuum of care as children transition to adolescence.



- Involving the community in outreach and paediatric treatment literacy, including phased age-sensitive disclosure.
- Gathering more strategic information for programme design through disaggregated data on children.



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20 Avenue Appia  
CH-1211 Geneva 27  
Switzerland

+41 22 791 3666  
distribution@unaids.org

[unaids.org](http://unaids.org)

