UNAIDS

UNAIDS PROGRAMME COORDINATING BOARD

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THIRTY-NINTH MEETING

Date: 6–8 December 2016

Venue: Executive Board room, WHO, Geneva

Agenda item 3

Updated gap analysis on paediatric HIV treatment, care and support

Additional documents for this item: *none*

Action required at this meeting – the Programme Coordinating Board is invited to:

See decisions in paragraph below:

99. Take note of the report and analysis of the gaps in children's access to HIV treatment, prevention, care and support services, as well as the effects of stigma, discrimination and structural barriers on mother's and children's health, and the need for psycho-social support for children and affected families.

100. Calls on Member States, with the support of the Joint Programme, to take all necessary steps to achieve the global and regional targets set out in the 2016 Political Declaration and the Start Free, Stay Free, AIDS Free framework.

101. Calls on the Joint Programme to support countries' efforts to achieve the elimination of mother-to-child HIV transmission (eMTCT) and WHO certification (or pre-certification) of MTCT.

102. Requests the Joint Programme to work with partners to further strengthen and analyse the effects of stigma and discrimination on children, adolescents and young women, and to support countries in implementing programmes to address those factors.

Cost implications for decisions: *none*

INTRODUCTION

1. This paper responds to the following decision points made by the UNAIDS Programme Coordinating Board at its 35th meeting held in December 2014:

   8.6 Requests UNAIDS to gather evidence and analyse the effects of stigma, discrimination and structural barriers on mothers' and children's health, and the need for psycho-social support for children and affected families, in partnership with children and adolescents living with HIV and their caregivers; and to report back at a future Programme Coordinating Board meeting;

   8.9 Requests UNAIDS to provide to a future PCB an updated gap analysis on paediatric HIV prevention, treatment, care and support.

2. Significant progress has been made in reducing new HIV infections among children and increasing the number of children living with HIV accessing paediatric HIV treatment. Still major gaps remain in several countries and locations in reaching women and children with timely and effective HIV prevention, treatment, care and support services, maintaining adherence and providing support for retention in treatment.

3. In 2015, an estimated 150 000 children newly acquired HIV infection. Overall new HIV infections among children have declined by 70% since 2000 and 56% since 2010. Nearly 1.6 million new HIV infections have been averted since 1995. About 870 000 children have access to antiretroviral treatment by mid-2016.

4. There has been rapid progress in accelerating access to paediatric treatment in the last two years alongside efforts to stop new HIV infections among children. Nevertheless, nearly 110 000 children died of AIDS related illnesses in 2015, equal to 2100 children dying per week. Significant challenges remain in scaling up early infant diagnosis, tracking mother-infant pairs, identifying older children living with HIV, providing treatment with the most optimal formulations and in a timely manner, and retaining them in care. Special attention should be given to tailored service delivery models that support adherence and ensure viral suppression across the age spectrum.

5. In the past two years a series of consultations took place between civil society, faith-based organizations, implementers, policy makers, the private sector and international organizations to consider options for a rapid scale up of access to testing and treatment for children. These included meetings convened in the Vatican City, as well as a high-level ministerial meeting on ending paediatric AIDS in Abidjan, Côte d'Ivoire.

6. The important role of faith-based organizations and facilities in reaching and serving children and families was documented at these consultations, and a daylong meeting with directors of pharmaceutical and diagnostic industries was convened to enlist the support and talent of private sector leaders in advancing science and tools for paediatric testing and treatment.

7. In May 2016, a meeting of 11 African Ministers of Health, numerous Deputy Ministers and senior national government officials, together with representatives of key international bodies, programme implementers and civil society, met in Abidjan to address the prevention of mother-to-child transmission and treatment needs of children living with HIV.

8. These discussions led to the conclusion that the Fast-Track approach of rapid treatment scale up in the next five years (2016–2020) would not be ambitious for children. It is estimated that 50 000 children would still die due to AIDS-related causes, deaths that could be averted with a more rapid scale up of timely interventions. To avert those deaths, a super Fast-Track approach would be required. The meeting recommended a new global target to reach 1.6 million children living with HIV with treatment by 2018. The 2016 Political Declaration on HIV and AIDS endorsed that target.

9. Almost all the priority countries of the *Global Plan to eliminate new HIV infections among children and keeping mothers alive* now offer lifelong HIV treatment to pregnant women living with HIV (option B+). This is contributing to the significant, positive impact on the health of women living with HIV, as well as to the reduction of new HIV infections among children.

10. Despite unprecedented progress in reducing the number of new HIV infections and AIDS-related deaths among women, adolescents and children living, these populations continue to face stigma and discrimination, and experience human rights violations. These range from denial of access to health services (including denials based on a demand for parental/spousal consent), forced sterilization and discrimination in health facilities, educational establishments and employment settings. While almost all countries have policies against such discrimination, those policies are unevenly implemented at grassroots level. Adolescents, in particular, face issues related to parental consent and discrimination based on social and cultural norms.

SECTION 1: GAP ANALYSIS ON PAEDIATRIC HIV PREVENTION, TREATMENT CARE AND SUPPORT

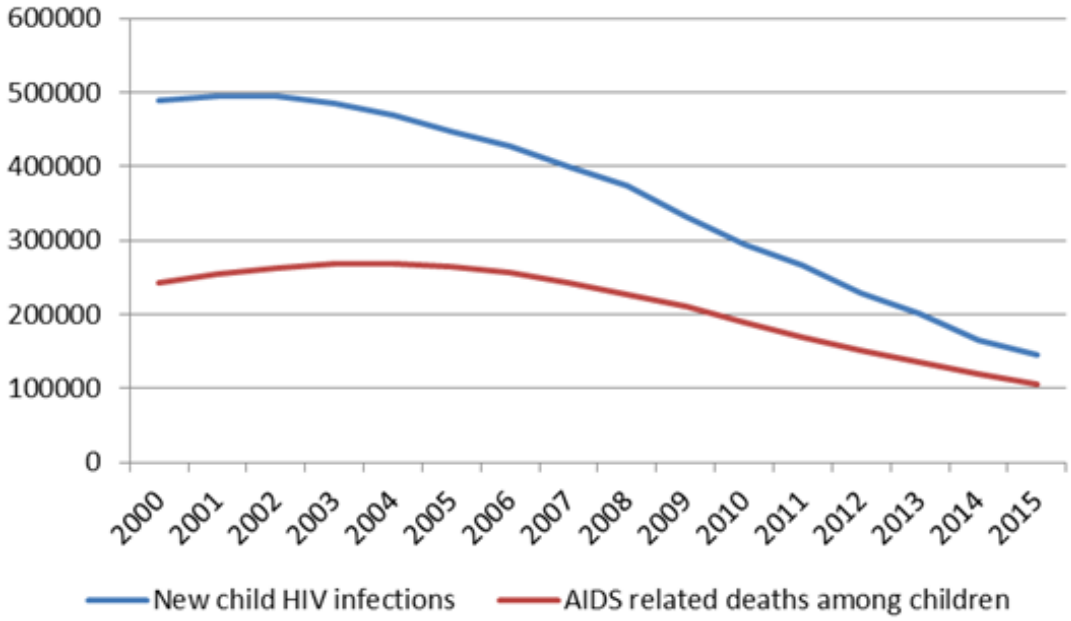
11. This section provides an overview of the progress made and the challenges that remain in eliminating new HIV infections among children and ensuring universal access to treatment for all children living with HIV. This section should be read in conjunction with the four UNAIDS reports that provide in-depth information on this issue:
    a) *On the fast track to AIDS-free generation* (http://www.unaids.org/sites/default/files/media_asset/GlobalPlan2016_en.pdf)
    b) *Get on the Fast-Track, the life-cycle approach to HIV, UNAIDS 2016* (http://www.unaids.org/en/resources/documents/2016/get-on-the-fast-track)
    c) *Prevention gap report* (http://www.unaids.org/sites/default/files/media_asset/2016-prevention-gap-report_en.pdf)
    d) *Start free, Stay free, AIDS-free:, A super Fast-Track framework for ending AIDS among children adolescents and young women by 2020*. (http://www.unaids.org/sites/default/files/media_asset/JC2869_Be%20Free%20Booklet_A4.pdf)

KEY EPIDEMIOLOGICAL FACTS

12. Globally, the annual number of new HIV infections among children 0–14 years of age have been reduced by nearly 70% since 2000 and by 51% since 2010. This indicates the remarkable progress made by programmes to stop mother-to-child transmission of HIV. At the same time, the annual number of AIDS-related deaths among children has been reduced by 57%.

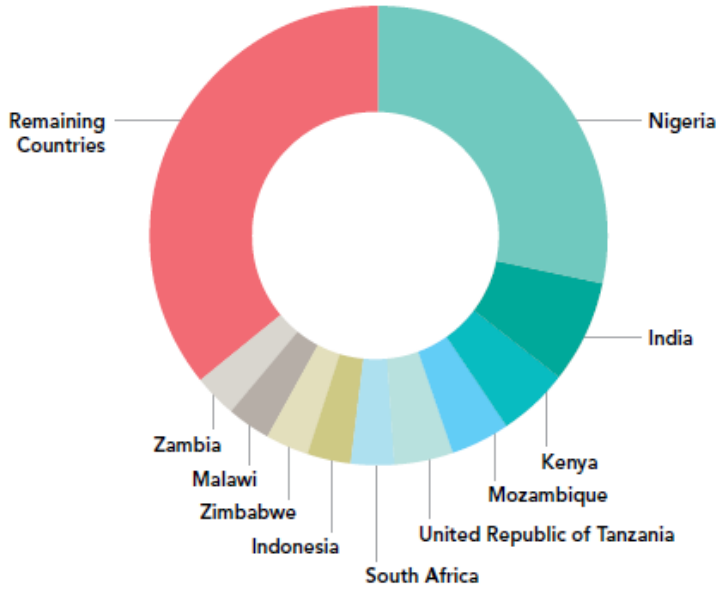
13. At the end of 2015 there were an estimated 1.8 million [1.5 million–2.0 million] children aged 0–14 years living with HIV, and there were an estimated 110 000 [84 000–130 000] AIDS-related deaths among children in the age group.

Figure 1. New HIV infections and AIDS-related deaths in children aged 0–14 years have decreased significantly since 2000



14. Vertical transmission of HIV is now largely confined to a relatively small number of countries: about 90% of new HIV infections among children occur in 26 countries, and half of new HIV infections occur in only 7 countries: Nigeria (40 000), India (10 300), Kenya (6 600), Mozambique (6 500), Tanzania (6 500), South Africa (5 100) and Indonesia (5 000). Nigeria alone accounts for more HIV infections in children than the next six countries combined.

Figure 2. Distribution of new HIV infections among children (0–14 years) by country, 2015

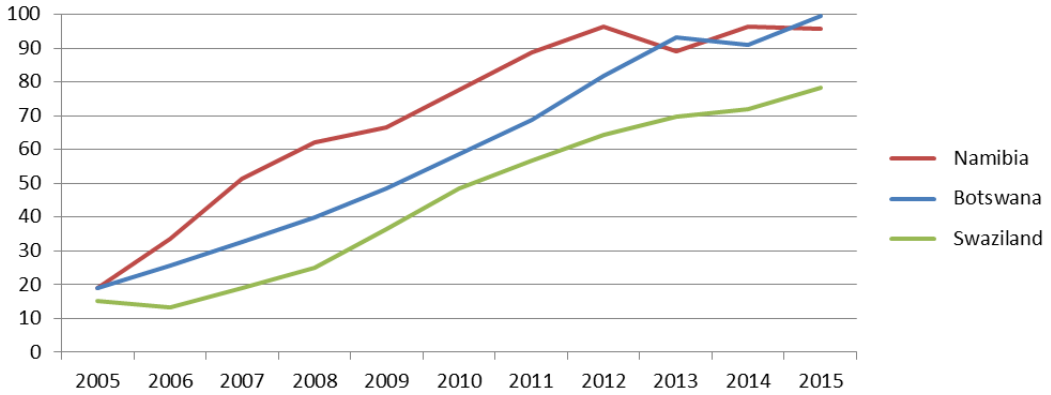


Source: UNAIDS 2016 estimates.

15. The coverage of services to prevent mother-to-child transmission of HIV has increased significantly. In 2010, 50% of pregnant women were receiving effective ARV regimens to prevent MTCT; by 2015 that had increased to 78%.

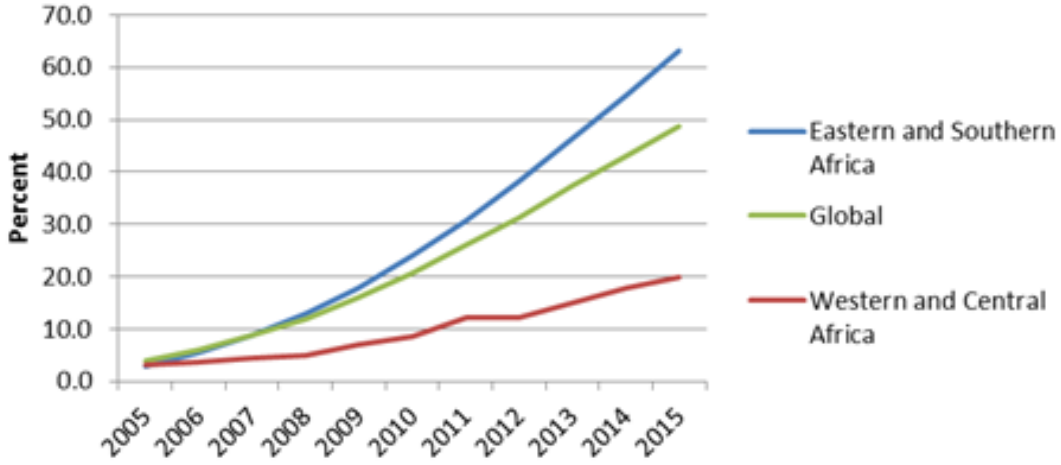
16. The number of children (0-14 years) on antiretroviral therapy has doubled over the past five years, from nearly 452 000 in 2011 to just over 910 000[801 000 – 947 000] in mid-2016, reducing the number of AIDS-related deaths in children by 44% in this period. Countries such as Botswana, Namibia and Swaziland have reached and started on treatment more than 80% of children living with HIV underscoring the fact that with concerted efforts, children living with HIV can be identified and provided with HIV treatment.

Figure 3. Percentage of children living with HIV receiving antiretroviral therapy, 2005–2015



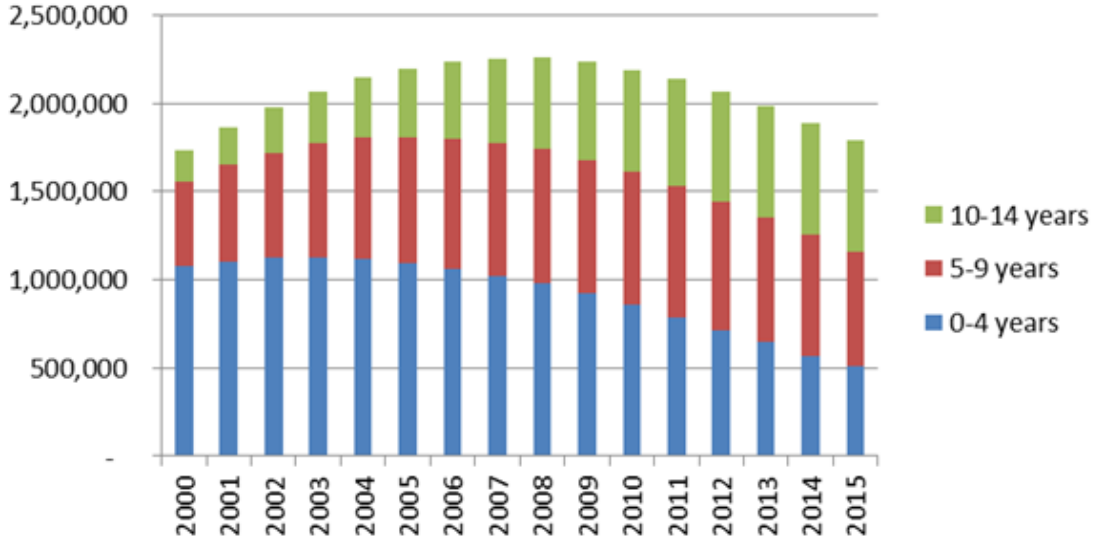
17. Progress in scaling up HIV treatment for children has been most rapid in Eastern and Southern Africa, where nearly 65% of children living with HIV access antiretroviral therapy (ART) currently. However, in West and Central Africa only one in five children living with HIV have access to HIV treatment.

Figure 4. Percent of children <15 years receiving ART in sub-Saharan Africa and globally



18. As a result of the decline in new HIV infections, the distribution of children living with HIV by age group has shifted over the past 15 years. At first, the majority of children living with HIV were in the young age group and few of those not receiving ART survived beyond five years of age. As access to ART increased for children living with HIV and fewer children were born with HIV, the proportion of children living with HIV was more evenly distributed across three age groups: 0–4, 5–9 and 10–14 years. Expanded scale-up of timely testing and treatment services is expected to increase the survival rates of children living with HIV, leading to more of those children reaching adolescence.

Figure 5. Global number of children living with HIV by age group



19. The distribution of AIDS-related deaths among children remains high among children under the age of five living with HIV. In the absence of effective treatment, almost 50% of children infected perinatally die within their first two years of life. Mortality rates are especially high in their first months of life. This underscores the importance of early HIV testing and access to treatment for infants.

Figure 6. AIDS-related deaths globally among children by age group, 2000–2015

The positive impact of HIV treatment on children with HIV means that they are increasingly surviving to reproductive ages. In 2015, approximately 40% of the estimated number of people living with HIV aged 15–19 years had been vertically infected.

GAPS AND CHALLENGES

HIV testing among pregnant women

20. Routinely offering HIV tests to pregnant women during their first antenatal visit and retesting them in their third trimester and then periodically during breastfeeding is the gold standard approach in settings with a high prevalence of HIV infection.[1] However, in some countries inadequate health care infrastructure, poor linkages between HIV and maternal-child health services, and lack of awareness of the importance of these testing opportunities keeps many pregnant women from taken an HIV test. In Nigeria, the most populous country in Africa, data show that only half of the estimated number of pregnant women living with HIV are tested for HIV. That gap contributed to an estimated 41 000 [28 000–57 000] new infections occurring among children in 2015 – more than one quarter of the global total.[2]

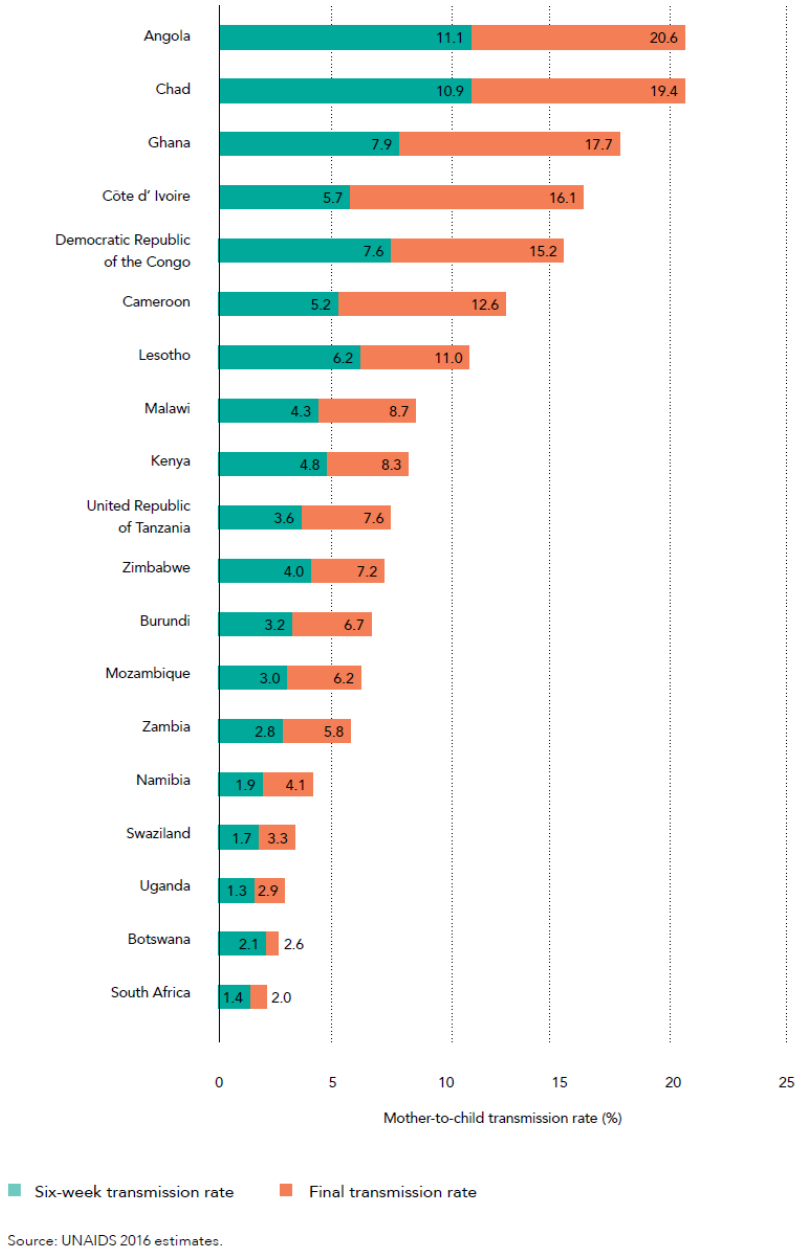
21. Nigeria and other countries with low HIV testing coverage among pregnant women share many common challenges, including shortages of HIV test kits due to weak procurement and supply chain systems. In addition, traditional beliefs, cultural practices, stigma and discrimination, a lack of confidentiality within health-care settings, and transportation challenges hinder access and contribute to under-utilization of HIV services. In the United Republic of Tanzania, for example, a study has found that concerns about the confidentiality of testing and test results, the quality of HIV counselling and testing services, and practical considerations such as accessibility and availability of ancillary services all affected the uptake of HIV testing services for pregnant women.[3]

Retention on ART during pregnancy and breastfeeding

22. Many country programmes emphasize the provision of antiretroviral medicines during pregnancy and delivery, but do not take sufficient steps to ensure that new mothers living with HIV are supported to adhere to the treatment in the months after giving birth. Without effective antiretroviral treatment for mothers, breastfeeding becomes a period of risk for HIV-exposed infants. Indeed it is estimated that about half of new HIV infections in children due to mother-to-child transmission occur during the post-natal period. Strong adherence to ART is vital to prevent transmission during this period. If mothers are not retained in care and not adequately supported to adhere to treatment, postnatal transmission could increasingly contribute to mother-to-child HIV transmission.

23. Many women are not aware that they need to remain on treatment during the breastfeeding period. It is vital to use all opportunities to improve mothers' awareness of the need to adhere to treatment and to re-supply them with medication once the baby is born, since women typically have less contact with the health system in the period after giving birth. Personal perceptions of wellness, along with possible side effects of ART, may contribute to mothers stopping or interrupting treatment.[4] Opportunities to assess maternal ART and the HIV status of the infant can be optimized during early childhood immunization visits.

Figure 7. Six-week and final mother-to-child transmission of HIV rates, selected countries, 2015



Source: UNAIDS 2016 estimates.

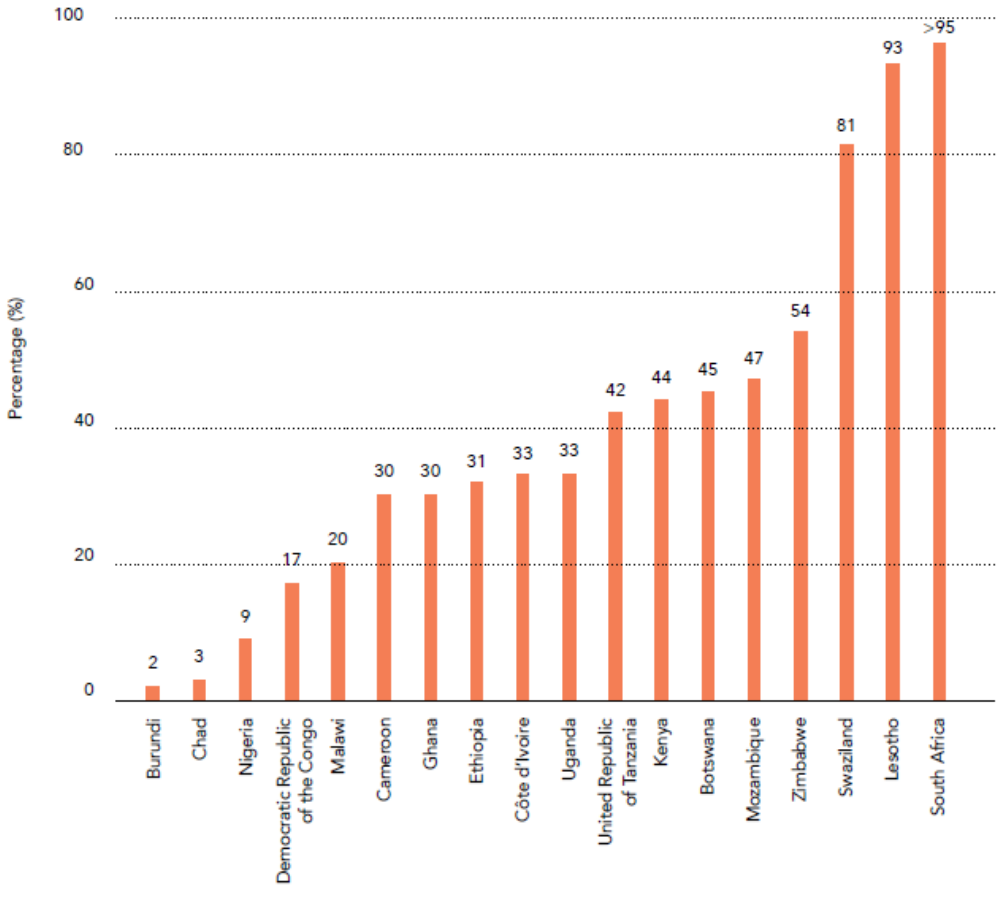
HIV infection during pregnancy

24. The proportions of women who acquire HIV during pregnancy and breastfeeding remain a concern. Strategies to prevent HIV acquisition among women during pregnancy and breastfeeding include partner testing to identify serodiscordant couples and the use of innovations such as pre-exposure prophylaxis (PrEP). Some high-burden settings (Swaziland and South Africa's KwaZulu-Natal province) are beginning to offer PrEP to HIV-negative pregnant women in specific situations.

Low levels of paediatric diagnosis and late initiation of treatment

25. A critical challenge for managing paediatric HIV is to track children who have been exposed to HIV and ensure that they are tested to determine whether they have acquired HIV infection. Children who test HIV-negative should be tested again during the breastfeeding period so those who acquire HIV can be identified rapidly. However, in many high prevalence countries fewer than 50% of HIV-exposed children are tested within eight weeks of birth. In 2015, only four of 21 Global Plan priority countries (Lesotho, South Africa, Swaziland and Zimbabwe) provided HIV testing to more than half the infants who had been exposed to HIV within their first eight weeks. Early infant diagnosis services are increasingly linked to services for preventing mother-to-child transmission, but implementation is weak in settings with low or moderate prevalence of paediatric HIV. A recent meta-analysis found that the yield of HIV-positive infants was very high in in-patient settings and nutrition clinics, respectively.[5] Based on these data, the World Health Organization (WHO) has strongly recommended routine testing for infants and children with unknown HIV status who are admitted for in-patient care or are attending malnutrition clinics.[6]

Figure 8. Percentage of infants born to women living with HIV receiving a virological test within the first two months of life, by country, 2015



Source: 2016 Global AIDS Response Progress Reporting.

26. Even when infants are tested early, inadequate transport, complicated communication systems, and fragmented and weak laboratory systems may result in lengthy delays between the collection of blood samples at clinics and the return of test results to caregivers. This can lead to loss to follow-up among those tested and to mortality among the infants who are HIV-positive.[7] A study in Zambia, for example, found that turnaround time from sample collection to the return of results was 92 days.[8] Innovative diagnostic assays to deliver testing closer to the point of care have been shown to sharply reduce and virtually eliminate such delays, thereby facilitating retention of the mother-baby pair in the testing and treatment cascade, and speeding up treatment initiation.[9]

27. Some countries are now testing children at birth.[10] In an effort to ensure that more infants living with HIV are diagnosed and initiate treatment early, South Africa launched national guidelines in 2015 which call for all HIV-exposed infants to be tested at birth and at 10 weeks. South Africa's experience with birth testing is being documented and evaluated to assess the impact on the testing and treatment cascade, and to overcome challenges, such as mothers not bringing their babies back for the 10-week test if they had tested HIV-negative at birth. WHO recommends that countries considering birth testing should simultaneously strengthen the traditional six-week programme to ensure optimal uptake and retention in the testing to treatment cascade.

Simpler and cheaper diagnostic tools

28. The most common virologic HIV tests for infants require complex laboratory instruments and highly specialized personnel, making it difficult for caregivers to provide consistent and timely results. In response to this challenge, several manufacturers are developing portable, point-of-care systems. Three point-of-care early infant diagnosis technologies are currently available, of which two are WHO-prequalified and one can be operated via a battery pack. Since these machines are small and portable, and can be operated by trained non-laboratory personnel, the technologies are likely to increase access to early infant diagnosis and to reduce loss to follow-up.[11] For that reason WHO recommends point-of-care early infant diagnosis testing to support earlier testing and quicker ART initiation. An evaluation of the first commercially available point-of-care and near-patient testing, conducted in several African countries, suggests that these tests are as accurate as laboratory early infant diagnosis assays.[12]

29. Early infant diagnosis is also becoming more affordable. The Diagnostics Access Initiative – a partnership between UNAIDS, the Clinton Health Access Initiative, the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund), the US President's Emergency Plan for AIDS Relief (PEPFAR) and UNITAID – in 2015 jointly negotiated a 35% price reduction for diagnostic kits produced by Roche Diagnostics,[13] at a price of US$ 9.40 per test.

Linking mother-and-infant pairs

30. If point-of-care diagnostics are to enhance paediatric outcomes they require parallel efforts to improve clinical service delivery. There are great opportunities for improvement. In a study in 22 health facilities in Uganda, less than 3% of infants born to women living with HIV were being retained in care in 2013. Interviews with women living with HIV with children aged between 6 weeks and 24 showed that 80% of retention problems were caused by forgotten appointments, scheduling conflicts, lack of transport, privacy concerns and fear of disclosure to their partners. That information was then used to improve the quality of care, and community representatives, such as peer mothers,

were engaged to locate mothers and babies who had been lost to follow-up. By February 2014, the surveyed health facilities were retaining more than 60% of mother-baby pairs.[14]

31. Many countries are piloting paper or electronic longitudinal registers for capturing data on HIV-exposed infants and mother–baby pairs, and prompting paediatricians to determine the final HIV status of the infant once the breastfeeding period ends. Electronic health records that link mother-and-infant pairs allow for joint tracking of mother-infant pairs, and enable babies to be tested and treated even when they are brought to the clinic for follow-up by someone other than the birth mother.

32. Malawi is piloting the use of mobile phone short message service (SMS) to send reminders to mothers who miss post-natal appointments.[15] SMS is also being used in Kenya, Mozambique, Rwanda, South Africa, Zambia and Zimbabwe to send the results of infants' virological tests from centralized laboratories to printers at community-level health facilities. A systematic review comparing paper-based systems to SMS systems showed that the latter approach speeded up the delivery of test results by an average 17 days.[16] In Kenya, the HIV Infant Tracking System, which sends computer alerts for EID and laboratory staff, and text messaging alerts to mothers has shown multiple benefits. It led to an increase in the proportion of HIV-exposed infants retained in care nine months after birth, it reduced turn-around times between sample collection, the receipt of laboratory results and notification of mothers, and it led to an increase in the proportion of infants living with HIV who initiate ART.[17]

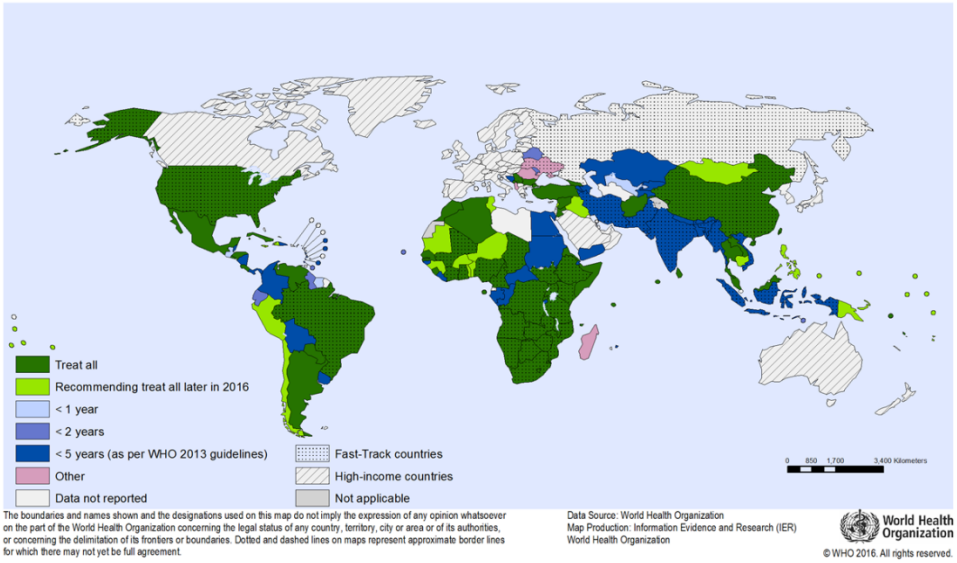
Timely initiation of treatment in children and maintaining virological suppression

33. In the past three years, countries opted for the earlier and broader use of antiretrovirals (ARVs) in children by adopting simplified policies that do not require CD4 testing to determine whether children (younger than 15 years) living with should start treatment.

34. Uganda's piloting of the Treat All approach in children was instrumental in the 2015 revision of the WHO treatment guidelines. Within a year of implementation, the approach has shown important achievements: ART coverage in children (younger than 15 years) increased from 22% in 2013 to 32% in 2014, and the elapsed time between diagnosis and treatment initiation was reduced from 18 days to 2 days.[18] The biggest increase in ART initiations was observed at lower-level health facilities (known as health centres in Uganda), which suggests that simplification promotes task shifting and the decentralization of paediatric ART. At the same time, a rapid assessment conducted in Uganda in July 2015 also uncovered challenges. They include a need to achieve reliable procurement of commodities, strengthen laboratory systems, and provide training, mentorship and ongoing supportive supervision.

35. As of October 2016, a large number of countries had adopted the Treat All policy recommended by WHO (see Figure 8). However, ART initiation occurs late, with the median age at ART initiation of 3.5 years[19] indicating that greater efforts are needed to achieve early diagnosis and treatment for infants living with HIV.

Figure 8. Recommended HIV treatment initiation threshold for children living with HIV in low- and middle-income countries and Fast-Track countries, October 2016



36. Access to optimal ARV drugs and formulations and a reliable supply chain is critically important to safely scale-up treatment in the context of limited drug options. While WHO guidelines advise the use more potent and tolerable drugs, countries have only recently begun shifting towards a more optimal use of drugs and formulations by adopting the optimal formulary of the Inter-Agency Task Team (IATT) for Prevention and Treatment of HIV Infection in Pregnant Women, Mother and Children. Improved formulations, such as lopinavir/ritonavir pellets, are becoming available more widely, and the LIVING study is currently piloing their use in a number of countries. A new drug class, integrase inhibitors, is now available for use in infants and children, and Raltegravir has been added as an option for second-line treatment. More evidence is being gathered to inform the use of Dolutegravir in children. However, greater efforts are needed to rapidly introduce new drugs and formulations once they become available. Simplifying and streamlining national regulatory processes is essential to increase access and ensure that the most effective drugs are available for use.

37. Partners of the Commitment to Action initiative (including the Clinton Health Access Initiative, the Drugs for Neglected Diseases initiative, the Global Fund, the International AIDS Society, PEPFAR, UNITAID and WHO) have been collaborating to improve the linking and coordination of existing work streams in order to promote a more rapid and efficient mechanism for the development and introduction of priority drugs and formulations for infants and children. Innovative approaches are being explored and closer public-private partnerships are being promoted to speed up introduction of improved medicines for children.

38. Monitoring infants, children and adolescents who are receiving ART is vital to ensure quality clinical care and management, and reduce morbidity and mortality. Due to ARV prophylaxis exposure during gestation and breastfeeding, as well as unreliable supplies of paediatric formulations and a high risk of poor treatment adherence, high rates of HIV drug resistance have been observed in infants, children and adolescents. Viral load testing should be used to monitor HIV-positive infants and children who are receiving ART to quickly detect treatment failure. Several technologies currently on the market use conventional laboratory-based technologies, while a number of point-of-care viral load technologies are in development and will be available soon. Viral load monitoring of

infants and children will allow clinicians to measure viral suppression. If elevated concentrations of the virus are detected, they can then initiate appropriate clinical interventions, including enhanced adherence counselling and potential regimen switching if drug resistance appears likely.

Differentiating service to provide better care to children and adolescents

39. Care for infants and children is still largely physician-led. Optimal approaches to task shifting should emphasize the sharing of responsibilities between physicians and non-physicians, and ensure that capacity building for nurses goes beyond training and includes ongoing supportive supervision and mentoring.

40. In the countries that achieved the greatest scale-up of paediatric ART, task shifting appears to have played a significant role. Nurse-managed paediatric ART models, such as nurse-initiated and managed ART in South Africa, have successfully empowered nurses and allied health workers to manage children with HIV. Swaziland and Zimbabwe have implemented similar approaches. In all those cases, paediatric nurse-managed ART was adopted after the rollout of adult nurse-managed ART.

41. In the United Republic of Tanzania, the integration of HIV services into under-5 clinics resulted in a doubling of the number of sites able to provide paediatric ART and an associated increase in the number of children newly enrolled in treatment. Uganda has successfully implemented a family-based ART care model and demonstrated a 40-fold increase in children enrolled in care and a 23-fold increase in children on ART. The family-based approach, pioneered by the multi-country MTCT-Plus Initiative, uses a community education model and involves setting up family clinic days with tailored health education messages to improve adherence to clinic appointments for children.

42. There is an increasing need for services to support adolescents so they can remain in care. As greater numbers of children receive treatment and survive into adolescence, it becomes vital to adapt service delivery models to ensure that adolescents receive age-appropriate care and support. The experience of Zimbabwe's Zvandiri programme shows how the introduction of adolescent-friendly HIV services in primary health care facilities, backed with integrated community based support, can promote a service that is responsive to the evolving needs and experiences of adolescents. The success of this approach depends on the sustained training and mentorship of facility and community cadres to recognize and effectively respond to the transitioning care needs of adolescents.

SECTION 2: STIGMA, DISCRIMINATION AND THE ROLE OF STRUCTURAL BARRIERS IN THE HEALTH OF MOTHERS, ADOLESCENTS AND CHILDREN

43. This section provides information and analysis based on a variety of published and unpublished data.

44. A broad range of human rights concerns have been documented in the context of HIV services for pregnant women, children and adolescents. They include stigma and discrimination, denial of health services, neglect and delays in the provision of care, low-quality care, and other negative attitudes and behaviours displayed towards pregnant women living with HIV in healthcare facilities. Some individuals are still being subjected to mandatory testing, informed consent to HIV testing and/or treatment and confidentiality are not yet universal.

45. More generally, adolescents, young people and women also encounter barriers in accessing services due to discriminatory third-party authorization requirements, such as parental or spousal consent. The involuntary sterilization of women living with HIV, forced abortions and the criminalization of the vertical transmission of HIV are among the most extreme manifestations of stigma and discrimination.

46. Many barriers interfere with access to care, and some of the most significant are associated with stigma and discrimination. Manifestations including perceived stigma and the experience of discrimination at health facilities. A qualitative study of HIV-positive mothers attempting to access PMTCT care in India, for example, suggests that women living with HIV perceive discrimination at multiple levels, including at the institutional level as well as in their interpersonal interactions with health workers.[20]

47. Barriers to access related to stigma and discrimination also affect adolescents from key populations, and range from fear of being mistreated by health workers to lack of confidentiality at health facilities.[21]

48. Women and children often experience intersectional stigma and discrimination that stems from more than one prejudice. A Canadian study[22] among HIV-positive black women has revealed an association between HIV-related stigma, gender, racial discrimination, and depression, suggesting that these interrelated forms of stigma and discrimination present barriers to treatment care and support.

49. In a French study[23] on perceived discrimination people living with HIV, 13% of participants reported experiencing HIV-related discrimination in the previous two years, while 8% reported discrimination in health care settings that appear linked to gender, sexual orientation and/or race. Migrant women from sub-Saharan Africa reported the highest levels of discrimination.

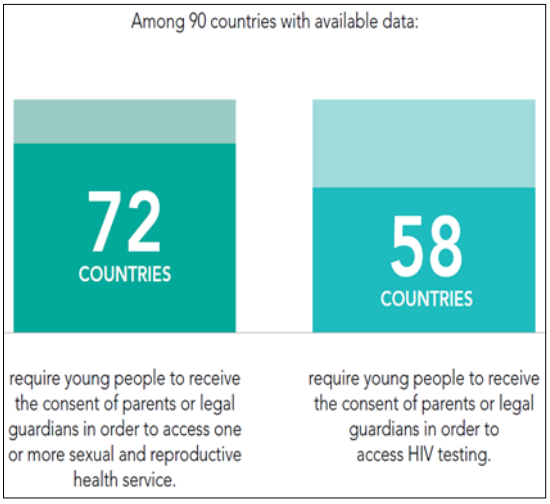
50. Women and children are more vulnerable than men to property grabbing, abandonment and violence as a result of their HIV status.

51. Health settings generally are ill-prepared to address the needs of women living with HIV who are also marginalized as sex workers or drug users, or due to being poor, young or disabled. Their children tend to be treated similarly. Consequently, stigma, discrimination and inequality contribute to negative health outcomes for children and their parents, and disproportionally affect poor or marginalized groups.

52. Third-party authorizations, or parental and spousal consent requirements, are barriers to accessing HIV services and sexual and reproductive health services, particularly among adolescents and women.

53. Greater efforts are needed to ensure that the legal framework is responsive and sensitive to the challenges that young people face when attempting to access HIV and sexual and reproductive health services. Improvements would include removing requirements for both parental and spousal consent when these present challenges for accessing necessary health services, especially for adolescent girls and young women.

Figure 9. Requirements for parental consent for accessing sexual and reproductive health and HIV testing services for young people, 2016



54. Many programme approaches assign the responsibility for behaviours and actions to individuals, without acknowledging that people, women especially, seldom enjoy complete autonomy to control their own bodies, health and sexuality. In 74% of sub-Saharan African countries with available data, less than 75% of women aged 15–49 years reported that they have the final say in decisions about their own healthcare.[24]

Women

55. In many settings, women report higher levels of stigma and discrimination than men.[25 26] A variety of discriminatory practices are reported in women's reproductive health settings specifically. For example, women frequently report pregnancy-related discrimination, including unexplained advice to avoid having children, inappropriate treatment or failure to provide care during labour, as well as forced or coerced sterilization of women living with HIV.

56. In one study in Asia, for example, 45% of females reported that they were advised not to have children following their HIV diagnosis, compared to only 18% of males. Women were also more likely than men to report being coerced into an HIV test (14% versus 10%). Over 15% of women reported undergoing mandatory HIV testing while they were pregnant or because of the illness of a child. In the same study, 17% of the female participants from Thailand were advised to have an abortion after testing positive for HIV during pregnancy.[27]

57. In another study in Kenya, 84% of health care workers reported that they believed it was appropriate to sterilize a woman living with HIV, even if this were not her choice.[28] These kinds of discrimination can have profound effects on efforts to eliminate mother-to-child transmission of HIV, since women who have faced discrimination or who anticipate HIV-related stigma in health care settings may be less likely to access pre- and post-natal treatment and care.

    In Cameroon, 13% of the 763 mothers living with HIV who participated in the Stigma Index reported they had been advised by a healthcare professional not to have a child, 2% reported being coerced into sterilization, and 2% reported being coerced in the last

12 months to terminate a pregnancy.[29] An environment of prejudice and social injustice is conducive to high levels of self-stigma, as well. In the Cameroon Stigma Index, 64% of women living with HIV with children reported experiencing at least one form of internalized stigma in the previous 12 months. Research shows that self-stigma acts as an important barrier to seeking and adhering to treatment and care services.[30]

58. Despite the consensus that HIV-related stigma and discrimination play significant roles in deterring pregnant women from utilizing HIV services, few studies have attempted to quantitatively assess how these different dimensions of stigma affect uptake of HIV testing among pregnant women.[31] In one study in the Ukraine, for example, researchers found that people who tested HIV-positive but waited more than three months before starting treatment largely cited the following reasons: fear that "health care workers would disclose status without [their] consent";" fear that "health care workers would mistreat" them; and previous negative experience communicating with health care staff.[32]

59. A study in Kenya[33] has shown that anticipated stigma regarding one's HIV status and its perceived consequences can be a barrier to acceptance of HIV testing for pregnant women, even in an environment where HIV testing in antenatal clinics is becoming the norm. The reluctance was more common among women than among men. The study also found that fear of stigma and discrimination from male partners were more likely to discourage taking an HIV test than fear of stigma and discrimination from other people (friends, family, co-workers, health workers etc.).

60. Research also shows that HIV-related stigma and discrimination affect pregnant women's decisions to test for HIV and enrol in programmes for preventing mother-to-child transmission of HIV programs,[34] and impede women's retention in those services.[35] [36] [37] [38]It has been estimated that, in some settings, more than half the HIV infections due to mother-to-child transmission can be attributed to the cumulative effect of stigma at various points in the cascade of services for preventing mother-to-child transmission.[39]

61. In Nigeria, which has the second largest HIV epidemic in the world, stigma and discrimination are highly prevalent. While discriminatory attitudes towards people living with HIV among women reportedly decreased between the 2003 and 2013 rounds of the Demographic and Health Survey, still only half of women surveyed said they would buy vegetables from a person living with HIV. Discriminatory attitudes among men increased between those two survey rounds.[40] Nigeria had the largest number of new HIV infections among children in the world in 2015: an estimated 41 000 [28 000–57 000], roughly equal to the total number of infections in children in the next eight countries combined. New paediatric HIV infections in Nigeria have been reduced by only 21% between 2009 and 2015, compared to the 60% average reduction in the other Global Plan priority countries in the same period.[41] The 2011 Stigma Index in Nigeria documented serious cases of stigma and discrimination in healthcare settings. Among the 306 mothers living with HIV who were surveyed, over 5% reported being coerced into sterilization after testing HIV-positive, 6% said they had been coerced to terminate a pregnancy, and 19% said they had been denied healthcare in the 12 months preceding the survey.[42]

Women from key populations

62. Women who inject drugs, especially when those using narcotics during pregnancy, often face stigma and discrimination, often in the context of being criminalized. The United Nations Office on Drugs and Crime has noted that, in some countries, drug use during

pregnancy can lead to automatic criminal charges and incarceration for the duration of the pregnancy or beyond.[43]

63. In a number of countries in Eastern Europe and Central Asia, for example, seeking treatment for drug addiction requires being registered as a drug user, which in turn may be automatic grounds for losing custody of a child. In the Russian Federation, pregnant women registered as, or deemed to be drug users have reported that their children were taken away from them in the maternity ward soon after birth.[44]

64. A qualitative study among pregnant drug users in the United States of America has found that the women would adopt various strategies to minimize the risk of being identified as a substance-user. Some of the women would isolate themselves from friends and family, hide or deny the pregnancy, time prenatal appointments so that persistent substance use would not show in drug tests, skip prenatal visits or avoiding prenatal care altogether.[45] While research indicates that pregnancy can be a powerful motivator to seek drug treatment, in places where drug use is criminalized or where drug use can lead to loss of child custody, pregnancy perversely can become an impediment to seeking care.[46]

65. Unfortunately, attitudes towards pregnant women who use drugs are often based on ill-informed ideas about drug dependence and motherhood. A large body of research indicates that the circumstances of poverty, social exclusion, malnutrition and violence in which many drug-using women are trapped, partly as a result of aggressive campaigns against drug use, adversely affect their children's opportunities to access health and education services.[47]

66. While largely understudied, stigma related to sex work is also experienced at the intersections of HIV and gender-related discrimination in health care settings.[48] In a qualitative study of sex workers in Asia, for example, "in three of the four study sites, sex workers reported experiencing discrimination and violence in health care settings by doctors, nurses, and other staff, including in relation to actual or perceived HIV status."[49]

67. In some contexts, HIV-positive sex workers also report being ostracized by other sex workers following their HIV diagnosis.[50] Some such sex workers report being expelled from brothels by owners or refused health care, while some health workers admit that they prefer not to provide services to sex workers.

Children

68. Maternal health and new-born outcomes are inextricably linked.[51] Addressing stigma and discrimination at all stages leading up to birth, during delivery and immediately afterwards birth are vital to ensure survival and good health outcomes among neonates.[52] Studies of interventions that specifically target stigma and discrimination to improve neonatal survival and health are rare. However, available data shows that stigma and discrimination related to social standing and health can significantly affect child health by impeding or skewing child health and development outcomes and pathways.[53]

69. Research on children affected by HIV has shown that HIV-related stigma amplifies the negative effects and economic deprivation resulting from parental illness, disability and death.[54] Results from a study at 11 sites in Cameroon showed that only 32% of infants with a positive HIV test result were alive and on treatment 18 months later. Stigma and discrimination could in part be contributing to these failures.[55]

70. Children living with HIV may experience stigma and discrimination in the community, at schools, in homes, and in other social settings. It can take the form of isolation, bullying, breach of confidentiality, or other acts that lead to anxiety, fear and confusion in the child.[56] In many cases, children whose parents have HIV experience similar stigma, even if they do not have HIV themselves.

71. Because parents may be equally fearful of stigma, they frequently impose secrecy around familial HIV, and the child may not be allowed to disclose their illness even if he or she knows what it is.[57] In schools, this means that teachers may not be aware that a child is living with HIV. In cases where children have to organize and manage their ARV schedules, for example in boarding schools, the need to conceal HIV status further complicates treatment, as the child has to hide in order to take their medicine. Where ARVs have to be taken with food, children may not have access to the food, or may not be able to control their meal schedules.[58]

72. All these factors exacerbate the effects of HIV on children's lives, and subject them to severe psychosocial burdens in addition to the more common childhood challenges they face.

73. The stress associated with HIV infection can affect even children who are HIV-free. A recent meta-analysis showed that the negative effects of parental HIV on children's psychological well-being, including stigma and discrimination, persists during the time that the parents are ill and even after their death. In studies in Zimbabwe, for example, children were aware of other children who were caring for sick parents, and performing other household chores.[59] Children may have to move to other families or even head households themselves. These are psychologically difficult experiences for, and there is need to provide them with stable and nurturing spaces, in addition to the medical and social interventions that are needed to help them manage their predicament.[60]

74. Many schools are not adequately prepared to support children living with HIV, due to interlinked factors that include shortages of resources, lack of information, fear and apprehension, and a generally over-burdened education system. Campbell et al have noted that in many cases, teacher-child relationships tend to be authoritarian and disciplinarian, and many teachers may not view their role as carers and empathizers. This drives a vicious cycle where children are unable to confide in teachers.[61]

Adolescents

75. Adolescents who are subject to discrimination are more vulnerable to abuse and other types of violence and exploitation, which contributes to putting their health and development at risk. They are therefore entitled to special attention and protection from all segments of society.[62]

76. Worldwide, adolescents in key population groups (including gay and bisexual boys, transgender adolescents, adolescents who sell sex and adolescents who inject drugs) are at a higher risk of HIV infection. These marginalized groups face discrimination and human rights violations, and they often are excluded from services".[63]

77. Young key populations also must be ensured a protective legal environment where their identities and the behaviour pertaining to their populations are not criminalized, and where their rights are respected, protected and promoted.[64]

78. There are few data about HIV prevalence and vulnerability among adolescents who inject drugs. A 2010 survey of street youth across multiple cities in Ukraine found that one-third of those aged 15–17 years who injected drugs are living with HIV.[65]

79. A study in Latin America estimated that 44–70% of transgender women and girls leave home or are thrown out of their home.[66]

80. Behavioural surveillance studies[67] suggest that almost one in five female sex workers in India begin selling sex before the age of 15 years.

81. Sexual minority stigma is associated with high-risk sexual behaviour by young men who have sex with men,[68] who may also be discouraged from seeking voluntary HIV testing and counselling and other essential prevention, care and treatment services.

Solutions: what it takes to address stigma and discrimination against women and children

82. Successful interventions to challenge stigma and discrimination involve a combination of strategies and approaches, engage a broad range of stakeholders, are led by or actively engage communities that are experiencing stigma and discrimination, and address crosscutting factors.[69] Promising interventions in a wide range of contexts also highlight the need for the involvement of gatekeepers and various change agents, such as local government leaders, teachers, police, media and health care providers.[70] [71] [72] Involving marginalized communities is essential for strengthening capacity, ensuring appropriate messaging and maximizing results.[73] In addition, addressing self-stigma is important for effective engagement of marginalized communities.[74] Addressing intersecting stigma and discrimination related to gender and age is also important in the context of HIV services, including prevention of mother-to-child transmission of HIV.

83. Research assessing the impact of interventions for preventing mother-to-child transmission suggests that the location of services is important.[75] Women living with HIV may be reluctant to access services for fear of experiencing stigma and discrimination in contexts that are manifestly associated with being HIV-positive, and confidentiality therefore must be ensured. For example, in high-income countries, there is increasing

support for providing mental health services in schools as a way to facilitate access to care for groups that typically would avoid mental health care support due to stigma.[76]

84. With respect to neonatal survival and health, a great deal of advocacy favours integrating services in a one-shop stop model where multiple services are accessed at a single location, an approach that could contribute to improved maternal and neonatal outcomes.[77] The limited evidence on stigma and discrimination reduction efforts that impact neonatal survival and health suggest that the provision of information in community settings is important to increase knowledge among groups that typically underuse available services.[78]

85. Effective efforts to eliminate mother-to-child transmission of HIV depend on the meaningful involvement of communities and on effectively addressing human rights barriers. Recognizing this, UNAIDS has worked with WHO and networks of people living with HIV (the Global Network of People living with HIV and the International Community of Women with HIV/AIDS) to develop and pilot a tool on human rights, gender equality and community engagement standards. The tool features among the instruments used to validate eMTCT of HIV and syphilis in countries.

86. A key consideration for eMTCT validation is whether interventions to reach the targets have been implemented in a manner consistent with human rights standards. No country can be validated for pre-elimination or eMTCT of HIV or syphilis if grave or systematic human rights violations occur in the context of eMTCT. Those violations include forced sterilizations, contraception or abortion, or widespread mandatory testing of pregnant women. Non-discrimination in the delivery of eMTCT services is an immediate obligation provided for in all human rights instruments. Addressing human rights concerns and violations in the context of eMTCT requires concrete actions at global, regional, country and community levels.

87. 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 the practice.[79]

88. In June 2014, WHO, UNAIDS, the Office of the United Nations High Commissioner for Human Rights, UN Women, the United Nations Development Programme, the United Nations Children's Fund, and the United Nations Population Fund 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.[80] Recognizing the need to facilitate global action to ensure discrimination-free healthcare, UNAIDS together with WHO launched an Agenda for Zero Discrimination in Healthcare in March 2016.[81] The initiative brings together key stakeholders to work towards the goal of ensuring that everyone, everywhere can access health services without discrimination. The initiative aims to address intersectional discrimination in all its forms.

89. Existing solutions must be customized to match the needs of adolescents who are at high risk of HIV, and who are subject to multiple injustices such as stigma, incarceration and violence. It is therefore important to invest both in intermediate high-impact actions and in efforts to bring about long-term social transformation that serves the best interests of adolescents.[82]

90. The next section describes country examples of action against stigma and discrimination faced by children, adolescents and women living with HIV.

Namibia – strategic litigation to challenge involuntary sterilization

91. The Legal Assistance Center, Namibian Women's Health Network and the Southern African Litigation Centre litigated a case brought by three HIV-positive women who had been subjected to sterilization in public hospitals without their informed consent. The Supreme Court's decision in *Government of the Republic of Namibia v LM and Others* affirmed the High Court's July 2012 order, finding that the Government had subjected women to coercive sterilization. It held that the practice of coerced sterilization violated the women's legal rights.[83] This decision has far-reaching consequences for HIV-positive women in Namibia and for those HIV-positive women elsewhere who have been forcibly sterilized. The ruling sends a clear message that governments must take concrete actions to end this practice.

South Africa – community-led engagement with the Commission on Gender Equality

92. In South Africa, following media coverage of lawsuits which the Government had settled out of court, several women living with HIV came forward to share their experiences of having been forcibly or coercively sterilized. However, many of the women were unable to litigate their cases since too much time had elapsed. To address this situation, the Women's Legal Center, in partnership with the International Community of Women living with HIV/AIDS recently filed a complaint with the South Africa Commission on Gender Equality calling for an investigation into the prevalence of forced, coerced and otherwise involuntary sterilization in public hospitals. They also requested general and specific relief for the women whose cases had been prescribed and to raise awareness of the issue. The Commission is expected to launch an investigation and to seek the testimony of women who have been subjected to forced or coerced sterilization.

Thailand – Government-led comprehensive effort to address stigma and discrimination in healthcare

93. Stigma and discrimination were found to be hampering efforts to ensure access to HIV testing, prevention and treatment services in Thailand, with about 60% of people living with HIV being diagnosed late. Thailand therefore prioritized stigma reduction and committed to reduce HIV-related stigma by half and to create mechanisms to protect the rights of people living with HIV and key populations by 2019. It is using evidence-informed activities and is tracking progress against measurable benchmarks.

94. Thailand is now systematically monitoring stigma and discrimination in healthcare settings. The Ministry of Public Health, civil society organizations, people living with HIV and key population networks, academia, as well as United Nations and US Government agencies have joined forces and resources. A simple, practical tool to measure stigma and discrimination in health care settings was developed and piloted in two provinces. The National AIDS Committee endorsed the use of the stigma measurement tool as a routine monitoring instrument; a national survey will be conducted every two years. At sub-national level, the tool has been rolled out in 22 provinces. The Ministry of Public Health is also rolling out an accelerated system-wide stigma reduction programme, with civil society and concerned communities committed and fully engaged. In-person HIV related stigma and discrimination reduction training for health care staff is being implemented in four priority provinces, with plans for national scale-up in 2017. E-learning is being developed to complement the in-person training and to ensure that all

health care staff, at all levels, receive training and necessary support. The existing health services quality assurance system, such as hospital accreditation, will assess completion of e-learning by health facility staff, which also counts towards continuous education credits. Thailand's experience shows that stigma and discrimination in health care can and should be measured routinely and addressed systematically.

SECTION 3: WAY FORWARD AND DECISION POINTS

WAY FORWARD: START FREE, STAY FREE, AIDS-FREE FRAMEWORK

95. A new global framework known as "Start Free, Stay Free, AIDS-Free", is guiding efforts to take the agenda forward. Co-chaired by UNAIDS and PEPFAR, the framework aims to end AIDS in children, adolescents and young people by 2020. It seeks to do so by building on key lessons learned from the Global Plan: the critical role of country ownership; putting women, especially women living with HIV, at the centre of policy discourse; strong monitoring and evaluation; and good coordination and strong technical assistance. The "Start Free" and "AIDS-Free" components are focused on achieving the 2018 targets for children agreed by the United Nations General Assembly:

    a. Reduce the number of children newly infected annually to less than 40 000 by 2018;
    b. Reach and sustain 95% of pregnant women living with HIV with lifelong HIV treatment by 2018; and
    c. Provide 1.6 million children aged 0–14 years and 1.2 million adolescents aged 15–19 years living with HIV with lifelong ART by 2018 (reach 95% of all children living with HIV).

96. The framework provides a menu of policy and programmatic actions that are designed to enable countries and partners to close the remaining HIV prevention and treatment gaps for children, adolescents and young women.

97. To implement the framework and realize the targets, the framework recommends action on four fronts:

    a. Political commitment and policy change;
    b. Service delivery;
    c. Community engagement; and
    d. Innovation and development of new products.

98. The actions for each of these components are outlined in the document *Start Free, Stay Free, AIDS-Free* (http://www.unaids.org/sites/default/files/media_asset/JC2869_Be%20Free%20Booklet_A4.pdf)

DECISION POINTS

The Programme Coordinating Board is invited to:

99. Take note of the report and analysis of the gaps in children's access to HIV treatment, prevention, care and support services, as well as the effects of stigma, discrimination and structural barriers on mothers' and children's health, and the need for psychosocial support for children and affected families.

100. Call on Member States, with the support of the Joint Programme, to take all necessary steps to achieve the global and regional targets set out in the 2016 Political Declaration and the “Start Free, Stay Free, AIDS-Free” framework.

101. Call on the Joint Programme to support countries’ efforts to achieve the elimination of mother-to-child HIV transmission and WHO certification (or pre-certification) of elimination.

102. Request the Joint Programme to work with partners to further strengthen and analyse the effects of stigma and discrimination on children, adolescents and young women, and support countries in implementing programmes to address those effects.

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ACRONYMS

AIDS	acquired immune deficiency syndrome
ARV	antiretroviral
ART	antiretroviral therapy
eMTCT	elimination of mother-to-child transmission
Global Fund	Global Fund to fight AIDS, Tuberculosis and Malaria
PCB	Programme Coordinating Board
PEPFAR	President's Emergency Plan for AIDS Relief
PrEP	pre-exposure prophylaxis
SMS	short messaging system
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNFPA	United Nations Population Programme
UNICEF	United Nations Children's Fund
UN	United Nations
US	United States
WHO	World Health Organization