

HIV SERVICE DELIVERY

MEETING REPORT

REPORT OF A CONSULTATION CO-HOSTED BY WHO AND
THE COALITION FOR CHILDREN AFFECTED BY AIDS

LEARNING SESSION ON HIV-AFFECTED ADOLESCENT MOTHERS AND THEIR CHILDREN IN SUB-SAHARAN AFRICA

13 DECEMBER 2019, GENEVA, SWITZERLAND



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1. SUMMARY

This learning session, co-hosted by WHO and the Coalition for Children Affected by AIDS, brought together 43 global thought leaders from the HIV, sexual and reproductive health, early childhood development, poverty reduction, rights, gender, exclusion and mental health sectors to develop an evidence-informed advocacy agenda for HIV-affected adolescent mothers and their children. The learning session had the following objectives:

- to identify gaps and consolidate key scientific and programmatic evidence on the scale and nature of the needs of HIV-affected adolescent mothers and their children and proven solutions to address them; and
- to establish a set of advocacy recommendations for changes for governments, donors, policy-makers and civil society.

The learning session was accompanied by a comprehensive evidence review (1); a video of young mothers from across Africa (2); and an advocacy briefing (3) on what needs to change to deliver an effective integrated approach for children and adolescents.

Below are the draft advocacy recommendations working groups created during the learning session.



Key advocacy messages

1. We have the evidence; we know what works; what we need now is coordination and leadership.

We can and should start now to deliver change for HIV-affected adolescent mothers and their children. This is a transformative issue that cuts to the core of gender equality, human rights and the rights of the child and obliges sectors to work together in new ways. Achieving change will take time and therefore requires political and donor leadership.

2. Adolescent mothers and their children are a vast and growing population being left behind.

Both mothers and children are more vulnerable to HIV, delayed early childhood development, gender inequality, poverty, violence, exclusion and poor health and education, which limit generations across a lifetime. Despite this, they are underserved; with many too far away, too poor, too stigmatized and discriminated against and too mentally or emotionally distressed to access services or remain in care.

3. Adolescent mothers and their children face a double burden of stigma.

Stigma associated with HIV is compounded by entrenched stigma surrounding young motherhood itself. Many adolescent mothers and their young children are rejected by their families, communities, school, clinics and other service providers.

4. Harmful traditional practices and social norms deny them access to information and support.

These include practices and norms associated with contraception, female genital mutilation, child marriage, gender inequality and toxic masculinity.

5. A holistic approach that addresses the comprehensive needs of the adolescent mother and child together is more effective, feasible and affordable.

The days of working in siloed sectors are over; rather we must combine services and support on HIV, health, education, protection, poverty, gender and other areas, in a tailored, integrated programme. Mental health support in particular requires far greater attention. We must support all adolescent mothers in areas with a high burden of HIV infection and not just the people already living with HIV. Any service in contact with an adolescent mother and child is a window to provide this holistic support.

6. Start early.

What happens to children during pregnancy and in their first 1000 days determines their path through life. Children born to adolescent mothers are more at risk of delayed development, and those born in areas with a high burden of HIV infection even more so. Equally, comprehensive sexuality education and positive gender messaging from early childhood are key to tackling the harmful traditional practices and social norms. A life-cycle approach is essential for delivering transformative change.

7. Men and boys are a key part of the solution.

We must work with them to tackle harmful traditional practices and social norms; men often have leadership roles in communities, services and political institutions and determine local policies and practices affecting adolescent mothers and their children; and improving their health-seeking behaviour would be a major step in reducing HIV infection among girls and adolescents.

8. Strengthening the capacity of communities and families is key.

Strong national policies and laws are important. However, these are only enacted when complemented by supportive and resourced communities and families. Moreover, community-based organizations are well placed to reach out to those unable to access mainstream institutional services.

9. The participation of adolescents is essential.

They know what they need; they are critical for providing peer support to each other; and they should be supported to participate in decisions that affect them, and in holding governments to account.

A set of key advocacy recommendations for donors, governments and civil society were developed (see later in the report).

2. BACKGROUND, OPENING STATEMENTS AND OVERVIEW

Adolescent mothers and their children have poorer outcomes in preventing the mother-to-child transmission of HIV and are less likely to receive or stay on treatment. They are also at the receiving end of a multitude of broader vulnerabilities, including those associated with gender inequality, poverty, violence, exclusion and poor education. For the adolescent mother and their children, this puts their health and well-being at risk and perpetuates a cycle of poverty and vulnerability, including HIV infection.

WHO and the Coalition for Children Affected by AIDS convened a learning session of scientific and programmatic experts to consolidate the evidence on why HIV-affected adolescent mothers and their children are being left behind and to deliberate on the multiple-level changes needed to improve their outcomes.

The objectives of this learning session were:

- to identify gaps and consolidate key scientific and programmatic evidence on the scale and nature of the needs of HIV-affected adolescent mothers and their children and proven solutions to address them; and
- to establish a set of advocacy recommendations for changes for governments, donors, policy makers and civil society.

Opening co-chair remarks

Meg Doherty, Coordinator, WHO Department of HIV —

Opened the learning session by emphasizing its importance to WHO, especially in the context of universal health coverage and leaving no one behind and the importance of collaboration, linkage and synergy with other initiatives including the nurturing care framework agenda and the Start Free, Stay Free, AIDS Free initiative. Forums for collaboration, advocacy and coordination need to be convened and supported, for which this learning session is a key example. The aim is to define evidence-informed advocacy recommendations for donors, governments and civil society that we can all champion together. The learning session will address two central questions on changes needed by governments, donors, policy-makers and civil society; and evidence showing that these recommendations are either required and/or effective. The need for effective collaboration is reflected in the dynamic range of participants from various sectors, including early childhood development, adolescent health, sexual and reproductive health, HIV, gender and mental health.



Lisa Bohmer, Chair of the Coalition for Children Affected by AIDS —

Gave a brief overview of the Coalition and her focus on children facing social and structural exclusion – those left behind. The agenda for adolescent mothers and their young children as being both especially vulnerable and least served needs to be recognized and put on the front burner. Evidence tells us that integrated programming is the way to achieve the Sustainable Development Goals and HIV targets for those left behind. In particular, mental health, nurturing care and social protection are three interventions that, when combined with biomedical support, can improve the outcomes of HIV-affected children and adolescents across multiple Sustainable Development Goals. We need a strong united advocacy agenda to take this forward both within the HIV sector and broader development sectors.



In accordance with WHO procedure, all the invited experts completed a form of declaration of interests for WHO experts before the learning session that WHO assessed for real or apparent conflicts. No other significant interests were declared.

Listen to young mothers

The Coalition for Children Affected by AIDS compiled and showed a short video with adolescent mothers from across sub-Saharan Africa. In it they highlight their need for holistic support, combining assistance on HIV with support on poverty, education, mental health, parenting and stigma. They also describe intense stigma from their own families, communities and service providers, which is a major deterrent to them accessing support.

Regina Guthold, Technical Officer, Department of Maternal, Newborn, Child and Adolescent Health, WHO —

Gave insight into three strategies that address the needs of these young mothers and their children.

- Governments have signed up for the Global Strategy for Women's, Children's and Adolescents' Health 2016–2030 and its goals. In 2016, adolescents were included as a central population. Without addressing the needs of HIV-affected adolescent mothers and their children, many of the targets will not be achieved, including around early childhood development.
- Global Accelerated Action for the Health of Adolescents (AA-HA!) is guidance that assists countries as they respond to the needs of adolescents. It includes needs assessment, landscape analysis and priority setting.
- Global Action for Measurement of Adolescent Health (GAMA) is an advisory group to WHO to improve the measurement of adolescent health and track progress. It seeks harmonized and consistent measurement for all adolescents. Indicators are being developed by this advisory group to track progress. Looking at adolescent mothers is key to carrying out effective programming. We must set targets for them and measure them properly.



Gretchen Bachman, United States Government, PEPFAR, Office of the Global AIDS Coordinator —

Highlighted the new PEPFAR guidance on country operational plans that emphasizes the intergenerational cycle of childhood and adolescence: pregnancy – childhood – adolescence and then back to pregnancy. Many girls do not have the opportunities they need to prevent HIV infection or unwanted pregnancy. These adolescents cannot be retained in care. These girls are afraid to go to the clinic or to tell their parents that they are pregnant. So many girls in the DREAMS (Determined, Resilient, Empowered, AIDS-free, Mentored and Safe) programme are in this position. Adolescent mothers are just one of the subpopulations PEPFAR addresses. They have received more visibility and what is required to provide them with client-centred care is more clear. However, we must not help them just because we want to accomplish only early childhood development goals; these girls need their own opportunities to thrive. Working with mother-baby pairs is vital and well as with fathers. And we must meet their needs in the community, at the community level. In looking forward, we need an intergenerational approach to risk and resilience. This is embedded within comprehensive PEPFAR programming. DREAM is a start, but we also need to look at the needs of the younger children as well.



Catherine Bilger, UNAIDS —

Reinforced that HIV-affected adolescent mothers and their children are an urgent issue. We are all encouraged to read the background paper to the UNAIDS Programme Coordinating Board (4), which contains key data on progress and challenges for children and young people. Many adolescents become parents; HIV infection among adolescents remains very high. In 2018, 310 000 women 15–24 years old acquired HIV, an average of 890 women per day, which account for 30–50% of all the people newly infected in this age group; and adolescents are less likely to go to clinics. We need to scale up solutions – many of which were mentioned in the paper for the Programme Coordinating Board. We must not only support those who are living with HIV; we also need to support girls and adolescents before they become infected and/or pregnant.



Chip Lyons, Elizabeth Glaser Pediatric AIDS Foundation —

Began by highlighting the limitless potential of HIV-affected adolescent mothers. The Stay Free Working Group held an evidence sharing on HIV prevention among pregnant and breastfeeding adolescent mothers on 22 October 2019 in Washington, DC, hosted by the Elizabeth Glaser Pediatric AIDS Foundation. This evidence sharing highlighted the urgent need for better and more disaggregated data. We also have to do a better job of analysing data quickly to ensure a rapid feedback loop and action taken. The global policy environment is largely sound. However, it is not always translated into actionable policy, strategies and activities at the country level. Those of us working at the global level need to acknowledge the resource needs on the ground and to be better informed about the progress and challenges at the country level so that we can concentrate our advocacy efforts where they are most needed. On the programme side, interest is increasing in providing young mothers with pre-exposure prophylaxis (PrEP). However, this requires very careful consideration, since trials in the United States of America and South Africa indicate poor continuation and understanding of PrEP among young populations and challenges around funding and acceptability to clinicians. There is also a lot of support for home-based and community-based services and linking clinic and community more, which was echoed in the recent paper for the UNAIDS Programme Coordinating Board.



Corinna Csaky, the Coalition —

Chip invited Corinna Csaky to comment on the evidence shared at a meeting in October 2019 on HIV prevention amongst pregnant teenage mothers, hosted by the Start Free working group. Corinna highlighted the innovative example of comprehensive, home-based support for adolescent mothers provided by the AIDSFree JUA (Jielimishe Uzazi Na Afya) Program (5) and the video (6) about it. Corinna urged different sectors to work together in a common agenda for HIV-affected adolescent mothers and their children. The JUA program is a powerful example of what we are all striving for."



Lorraine Sherr, University College London and founding member of the Coalition —

Presented the results of an evidence review (1). Although there are many studies on HIV and AIDS and many on teen pregnancy, only 29 studies have examined HIV and AIDS, teen pregnancy and children together. The issue of HIV-affected adolescent mothers and their children is broad and cuts across many Sustainable Development Goals. Sub-Saharan Africa has an estimated 11.4 million adolescent mothers. However, UNAIDS data covers from 15 to 24 years old, so we cannot disaggregate those who are adolescents (15–19 years old). By age 18 years, 42% of urban and 50% of rural girls have become pregnant. Adolescent mothers and their children have a higher risk of acquiring HIV and are less able to access support.



Adolescent mothers living with and affected by HIV are more at risk of neurocognitive delays, physical and mental problems, antiretroviral therapy non-adherence, low retention in care, violence and early mortality. Mental health problems during adolescent pregnancy are profound and can lead to anxiety, trauma and suicidal behaviour. Adolescent mothers living with HIV have often been sexually infected. They are far less likely to engage in antenatal and postnatal care, schooling, early childhood development support or prevention of mother-to-child HIV transmission.

HIV-infected adolescent mothers have much lower rates of accessing and adhering to antiretroviral therapy in programmes for preventing mother-to-child HIV transmission and high post-birth dropout rates.

The children born to adolescents living with HIV – both HIV-exposed but uninfected and those who are born positive – have a higher risk of cognitive delays. Mother-to-child HIV transmission is being prevented very well, but there is a high post-birth dropout rate and adherence is low. These children also face a multitude of socioeconomic and structural issues and are more at risk of poor nutrition and schooling.

Adolescent fathers are the forgotten half. They are excluded from the literature, and there is very limited evidence about them from sub-Saharan Africa. We must not leave them out.

The literature really focuses on the negative aspects of young motherhood. However, if all the barriers are removed, then teen mothers can be good mothers. Being a young mother is not a crime, and we must go in with no judgement.

HEY BABY is a longitudinal study of 1025 adolescent mothers in South Africa, one third of whom are living with HIV. Elona Toska presented new unpublished data from this study: 51% of these adolescent mothers had their first child before 18 years; 25% are living in rural areas; 24% live in informal housing; 83% lack basic needs; 28% do not have enough food; 29% are not in school more than one year after having their child; and they report higher suicidality and mental health issues; 6% never started antiretroviral therapy during pregnancy and 34% started after the end of first trimester; 10% stopped taking antiretroviral therapy during pregnancy and breastfeeding.

Chewe Luo, UNICEF —

Who thanked Laurie Gulaid and Alice Armstrong of the UNICEF Eastern and Southern Africa Regional Office (ESARO) who developed the slides, highlighted that there are few data on this particular population, despite the great need. Chewe presented programming supported by UNICEF ESARO and invited participants to feed in additional work they are doing:

- strengthening national frameworks in three countries: for example, in Botswana, pregnant and adolescent mothers are now within the National Multi-sectoral Framework and Operational Plan for Adolescent Health and Nutrition; United Republic of Tanzania standard operating procedures call for enhanced counselling of pregnant and breastfeeding adolescents:
- supporting peer-led interventions in four countries: for example, Africaid Zvandiri has mobilized mentor mothers in Zimbabwe, resulting in viral suppression among 93% of adolescent mothers engaged in the programme after eight months; in Malawi and South Africa, mothers2mothers programmes have achieved 98% of adolescent mothers on antiretroviral therapy, and 93% are retained in care; and
- generating evidence: for example, working with the government and mothers2mothers in Malawi to generate intervention research on mentor mothers; supporting a national knowledge, attitudes and practices survey in Zambia to determine adolescents' and young mothers' knowledge of sexual, maternal and reproductive health; and supporting a mixed-method study of adolescent mothers in Zimbabwe, which won the ICASA research prize. UNICEF welcomes support from the Coalition to help continue to interest researchers in generating the data we need.



There are major gaps in the programming response: absence of at-scale and sustained interventions – programming is often boutique and in silos; there is persistent stigma surrounding adolescent motherhood; the lack of data – especially age and sex disaggregated and outcome related; lack of data systems for longitudinal tracking; insufficient focus on pregnant women who are HIV free in high-burden settings; inadequate numbers of health-care workers who have capacity and are adolescent friendly; and weak coordination and lack of effective referral pathways, especially for multisectoral programming.

Key lessons learned: we should not have a programme just for HIV negative or positive – it should just be for adolescent mothers, who all need this holistic support; give priority to and support government leadership; emphasize scale and sustainability from the start; use and strengthen data; create adolescent-friendly antenatal and postnatal care; ensure that peers and community workers are well linked to health facilities; and develop packages and referral pathways that address holistic needs.

UNICEF has developed a set of calls to action for this agenda: invest in universal health coverage; reinforce the workforce; scale up the use of electronic medical records; engage adolescents in all their diversity at every stage; give priority to adolescent health – including physical and mental health; adopt policies that are in the best interests of adolescent mothers and their children, including around the age of consent and comprehensive sexuality education; increase resources for tackling stigma; and expand multisectoral programming, including with social protection, economic opportunities, early childhood development and nutrition.

Comments from participants

Deborah von Zinkernagel, UNAIDS —

Commented that the literature review is missing data on the cost of inaction.

Audrey Pettifor, University of North Carolina —

Has been following a cohort of adolescent girls receiving cash transfers. Alison Groves, Drexel University is also looking at young mothers. We are seeing that the risk of acquiring HIV after pregnancy is almost double among those that become pregnant before age 18 years. They also drop out of school.

David Sunderland, UNFPA —

UNFPA's goals are very relevant to this population: zero unmet need for contraception; zero preventable deaths; and zero gender-based violence. More than 1200 commitments were made surrounding these goals at a recent UNFPA Summit in Nairobi, 43% of which were on sexual and reproductive health and rights and 21% were on addressing gender-based violence. Within these commitments, there will be some useful ammunition for this group. UNFPA also works on comprehensive sexuality education. How do we link the national and global level more effectively? On 11 November 2019, the Global Prevention Coalition convened many countries at the ministerial level on comprehensive sexuality education. Multisectoral involvement is key, and we should include UNESCO, ILO and all those in the joint programme. UNFPA held a meeting of the joint programme on progress towards Sustainable Development Goals indicator 5.6.2 – enabling laws on reproductive health care, and the minimum age to access voluntary counselling and testing was identified as a major barrier. This should be a focus for this group.

Priscilla Idele, UNICEF Office of Research – Innocenti —

We are still talking about the same issues 10 years down the line. We already have sufficient information. We know what needs to be done. More data will not resolve the problem. Mental health is becoming a huge issue, not just for adolescents living with HIV. We must intervene before they turn 15 years. Our programming should be holistic. And it should support all adolescent mothers in areas with a high HIV burden regardless of their HIV status.

Chip Lyons, Elizabeth Glaser Pediatric AIDS Foundation —

Kenya has had a 19–31% increase in teenage pregnancy and an alarming increase in vertical transmission, also in other countries. We do not have sufficient guidance for 15-year-olds who present as HIV negative and then seroconverts during breastfeeding. This is happening even in areas of full saturation, such as Homa Bay.

3. WHAT NEEDS TO CHANGE – TACKLING EXCLUSION

This was a dynamic discussion chaired by **Wole Ameyan of WHO**. It sought to address the following:

- improving the human rights and legal environment;
- what role can men and boys play and how best to support them;
- enabling adolescent-led initiatives to support those harder to reach;
- tackling poverty and inequality among adolescent mothers living with HIV;
- strengthening sexual and reproductive health rights among HIV-affected adolescents; and
- tackling stigma – associated with adolescent pregnancy and with HIV and AIDS

Venkatraman Chandra-Mouli, Department of Reproductive Health and Research, WHO —

Reflected on trends in adolescent sexual and reproductive health in the 25 years since the International Conference on Population and Development. This is elaborated upon in a new set of journal articles, co-authored by WHO, in the *Journal of Adolescent Health* (7). Adolescent mothers and their children are a global issue, not only relevant to sub-Saharan Africa. Despite adolescent sexual and reproductive health being identified as a priority at the historic 1994 International Conference on Population and Development, this issue did not feature in the Millennium Development Goals.



Adolescent mothers access antenatal care later and less and are much less likely to seek skilled care. A new WHO study published in *The Lancet* (8, 9) looking at how women are treated during childbirth in Nigeria, Myanmar, Guinea and Ghana describes chronic mistreatment of adolescent mothers: 43% are mistreated, mostly half an hour before childbirth and 15 minutes after childbirth. They are beaten and verbally abused by doctors, nurses and midwives.

Much good work is already being done. We must learn from it and scale it up. Even in resource-constrained settings change is possible; for example, Ethiopia has transformed its basic health programme – reduced female genital mutilation, maternal mortality and greatly increased the use of contraception. What is evident is that change takes time – examples from Ethiopia, UK and other countries shows that it takes 15 years. But governments want results in three years. We also need action at multiple levels – from the girl to society. There is money on the table for child marriage and for adolescent contraception and different sectors must work together to make the most of it. The ECHO trial (10) is just one example of this. We need to get out of our comfort zones and better engage a variety of stakeholders, including faith-based organizations.

Quarraisha Abdool Karim, CAPRISA, UNAIDS Collaborating Centre for HIV Research and Policy —

Adolescence is a period of transition between being a child and an adult. We have global statistics on children and separate statistics on adults, but not those 15–19 years old. There are more data on this age group at the country level; the best source of data on this age is from antenatal clinics. Nevertheless, some countries in sub-Saharan Africa consider sex among people younger than 18 years statutory rape, and staff may not want to get wrapped up in legal requirements.



The circumstances through which an adolescent becomes pregnant are critical, because it often results from unequal power relations and violence. It is often legalized through child marriage, which protects older men. Maternal mortality rates remain very high – more than 40% of these deaths in some countries are among adolescent mothers. Their bodies are not ready for pregnancy. Her right over her child is

in question, since she is a minor, regardless of whether she is married or not – she cannot give consent for her child's access to services. In some cases, adolescent mothers are entitled to antenatal care and other therapeutic services but not to preventive services. Power issues and patriarchy are paramount in many settings. For example, female genital mutilation is still extremely common. We must also not forget displaced populations in our endeavours.

There needs to be more emphasis on preventing unplanned pregnancies, emergency contraception, PrEP, gender-based violence, child marriages and termination. There must also be greater consideration of the father. Fathers take latent responsibility. And this is reinforced by the fact that there is no documentation in programmes for preventing mother-to-child HIV transmission and for antenatal care on who the father is. So all the burden falls on the mother. Terms and procedures must acknowledge fathers.

We have the data; we already know what to do: education on sexual and reproductive health and rights for 9- to 14-year-olds. We all agree that keeping girls in school is important for their life trajectories. Nevertheless, schools have a gap on sexual and reproductive health and rights, which is either too little or too late. We must start that at 9–14 years. That knowledge is important. It must be provided to young boys and girls. Women-headed households predominate in many settings in sub-Saharan Africa. So young girls grow up assuming that they will also be single mothers. We can only change this if we educate girls and boys from an early age about rights and choices.

Use antenatal care and programme platforms for preventing mother-to-child HIV transmission for providing broader services: Almost every sub-Saharan African context has very strong programmes for preventing the mother-to-child transmission of HIV. This provides data on everyone who is pregnant. We focus so much on the mother living with HIV and keeping the baby HIV negative that we have forgotten about the uninfected mothers. An adolescent mother is at great risk of having further births and becoming HIV positive. We must support HIV-negative mothers before this happens. We must also look at the father and ensure that he takes more responsibility. Preventing the mother-to-child transmission of HIV is a low-hanging fruit to monitor temporal trends and measure whether interventions are having impact.

Include adolescents: they know what they need and what they want. They must be at the table and be supported in having their own voice. This includes research – we must not exclude adolescents for ethical reasons. We have to focus on each country individually. The SRHR Africa Trust reviewed the legal barriers to age of consent in Africa (11). But we have to be looking much more holistically at the country level to create guidelines to ensure that consistent and accessible language is used to address the disparities between laws versus ethical guidance versus social norms. Otherwise, we will continue to produce lovely documents that have no local ownership or teeth. They are meaningless to people on the ground.

Karen Austrian, Population Council —

Economic and community constraints are paramount. These girls are living in extreme poverty and in contexts in which social norms prevent them from accessing school or reaching their potential. We must address this broader context if we are to address the needs of these girls. Tackling their poverty should be our priority – if they do not have the money to eat or feed their children or to access other services, then no other outcomes will improve. If we do not think about broader needs in a context of poverty and the constraints it imposes on the lives of adolescent girls, the potential of all these other interventions is severely limited. Poverty alleviation is paramount and must be included as part of a multisectoral approach.



One of the challenges is that mechanisms are not set up to foster multisectoral work. It is the same group of girls we want to have training, access to health, cash transfers etc. But it is in the purview of several different ministries. The strong devolved system of governance in Kenya is one example of multisectoral coordination being easier: in Kenya at the county level it has been easier to work at the district level platform, where it is easier to get different ministries to sit together.

Lycias Zembe, UNAIDS —

It is important that we highlight the role of men. Adolescent mothers are living in a complex reality. To empower an adolescent girl when you do not empower the men around her is not effective. The men around her do not have health-seeking behaviour; from testing to treatment, men are not accessing services. Further, the rite of passage in many traditional settings in sub-Saharan Africa often promotes concepts of masculinity that are toxic and promote violence. The result is that women are not free to make their own decisions about their own health. Very few men are involved in making decisions with their partners.



We must try to address gender norms in traditional settings. For example, the UN Women He for She programme in north-western sub-Saharan Africa partnered with the church to promote gender equality in local taverns. It used taverns as the space to change the message and has become a beacon for other settings. The rite of passage messaging by churches and others is a key point at which young boys receive messaging on how to treat women. Men must be present to see and hear the realities of what adolescent mothers are going through as a result of toxic masculinity.

We must transform the health-seeking behaviour of men. In doing so, we must involve those who promote toxic masculinity – to be champions in their own communities. Voluntary male circumcision is another opportunity. If men know the importance of testing for HIV, they are more likely to ensure that their partners and children also know their status. Self-testing is going to be another game-changer for men. Let's change the narrative so that men have good health-seeking behaviour for their own right and well-being and not just to benefit others.

Comments from participants

Chewe Luo, UNICEF —

Although antenatal care is an important platform, we must not forget about postnatal care. What can that platform give us that we are not tapping into? A lot of the excellent information collected at antenatal care clinics is not reported upwards or to other sectors. They collect key information at antenatal care visits, including the age of the girl, whether she is married and other information about her health. We should be using these data to better understand these girls and from there analyse where the legal systems, services and social norms need improving. We can also provide a holistic approach tailored to each girl.

Bernadette Ng'eno, United States Centers for Disease Control and Prevention —

We must not ask adolescent mothers to promote health-seeking behaviour among their male partners. Most have failed to negotiate safe sex and are highly unlikely to be able to. We must look to other strategies to promote health-seeking behaviour among men. For example, Men take Responsibility is an effective example of a community outreach programme for men 20–30 years old that provides out-of-hours health services. We must identify what is already happening across sectors and ensure that it is well integrated. Most is siloed in some way. How can we ensure that every girl who comes in contact at any entry point leaves with the holistic support she needs? Working across the ministries is critical. The adolescent boy is also very important. In Kenya, we have a peer support intervention for girls living with HIV provided as part of antenatal care. Some boys come along when they are encouraged to participate in parenting. This is a key opportunity to explore and through which to address other issues.

Monica Oguttu, KMET —

In many settings, we already know what should be done, but the community leaders will not allow many of them. For example, many do not allow information on sexual and reproductive health and rights to be given to girls; adolescent mothers are banned from attending school. This is a barrier in every context and can spill over to other countries.

Alison Groves, Drexel University —

Strong policies are often not enough. Even in the countries that have a policy on supporting adolescent mothers to return to school, many of these policies are unclear or are not enacted.

Audrey Pettifor, University of North Carolina —

We have started working with men in South Africa. In this context, we do not see a lot of cohabitation. We gave out self-testing kits to adolescent mothers to give to their friends and partners. It was not very effective. Instead we should target men in a separate context. Sonke Gender Justice is an important organization that targets young men in the community on their own. Outreach testing is what they want – they cannot or will not come to the clinic. Most are unemployed – it is not just the clinic hours that are the barrier to their uptake.

Nicola Willis, Africaid Zvandiri —

Boys are a neglected group. We now have data from two trials that show failure of viral suppression on antiretroviral therapy is higher among boys; they struggle around disclosure for many reasons – including due to suicidal ideation. We should not look at boys as the source of HIV infection. We must address their needs and rights. They have significant mental health issues. Growing up without fathers, profound grief and anger around absent male role models. This has implications for how they are able to approach healthy gender and sexual relationships.

Elona Toska, Cape Town University —

Parenting is hard in any context – how do we help these young people enjoy it and have the skills to nurture their children effectively?

Gretchen Bachman, United States Government, PEPFAR, Office of the Global AIDS Coordinator —

Girls don't always have a choice. We know from the violence surveys that rates of forced and coerced sex are high. When we started rolling out DREAMS, we had examples in the curricula that put the responsibility on girls to manage their own consent. We now have a strong focus among 9- to 14-year-olds on what is a healthy relationship, informed consent and protection against HIV. We have a new faith and community initiative – focused on expanding community-based interventions with men and boys to address social norms around violence. This will be done in 10 countries, including Kenya.

4. WHAT NEEDS TO CHANGE – SUPPORTING NURTURING CARE

This was a dynamic discussion chaired by **Lynette Mudkenye of REPSSI (Regional Psychosocial Support Initiative)**. It sought to address the following:

- mobilizing governments, policy-makers and civil society around nurturing care;
- supporting HIV-affected adolescent mothers to provide nurturing care;
- building mental resilience among HIV-affected adolescent mothers;
- HIV-exposed uninfected children – what can we say about those of adolescent mothers in particular; and
- opportunities for integrating HIV-exposed uninfected children into the nurturing care framework.



Lynette Okengo, African Early Childhood Development Network (AfCEN) —

In the early childhood development community, we talk a lot about the child but not so much about the caregiver. We must not separate the two. AfCEN advocates for children 0–8 years old. We are based in Kenya but cover the whole continent. We bring together non-state actors to strengthen their voice. Implementation around early childhood development is a huge challenge, and we advocate for governments to put money and plans behind policies. The African Union is an important stakeholder, as is the child rights forum. We have also established an early childhood development education cluster within the African Union to advocate to ministers and high-level advisers. In recent years, early childhood development has become visible in meetings, communiqués and action plans; the Organization of African First Ladies has also been working a lot with HIV and AIDS and now has a new strategy on responsive caregiving. Agenda 2063 of the African Union strongly emphasizes young people as an important window of opportunity for our advocacy in the African continent.



Monica Oguttu, KMET —

We need to act now. Most adolescent mothers we work with have lost parents because of HIV. We worked at the community level to create a local integrated package of support for adolescent mothers. The result was the Sisterhood for Change programme. It began as a safe space for them to come to receive counselling and provide services. However, over time we realized that much more needed to be done. Stigma against these mothers and their children is chronic; many community members do not want their children playing with those of adolescent mothers, even more so when they are living with HIV. So we started a nurturing care centre where the adolescent mothers could come and live with their children for 3–6 months. There they both receive a holistic package of support including nutrition, antenatal care and HIV. Crucially, the centre also provides childcare for these young mothers, enabling them to study or to go out to work. And it provides peer support so that the young mothers can talk freely about the issues affecting them. After 3–6 months, most young mothers find employment and move out of the nurturing care centre. For those who struggle, they can return to receive vocational training. We also have a “freedom house” for young mothers to recover from gender-based violence.



We must give priority to engaging adolescents; they know what they need. We must ensure that the community owns, designs and delivers services. All community stakeholders are important: faith leaders, chiefs, women, mothers and others. For example, in Kenya, a father or a brother pays most of the school fees for a girl, so they must be part of the solution. This is this is key for sustainability. We need political will and to bring the government with us right from the start, so that change is sustained beyond donor funding. We need more advocacy; we need the young people to tell their story in the community and in the media – stories move us to act. We also need services to be better coordinated. Most of us are working in silos. We need to map multiple service providers in any given context so that we can plan together and achieve clarity on each other’s roles and responsibilities. We also need to share data between sectors.

Tarun Dua, WHO —

It is very important that mental health is on the nurturing care agenda. Mental health of men and boys is just as important as those young mothers. We know that pregnancy and childbirth are risk factors for mental health, especially in low- and middle-income countries; on in every three or four mothers will have a common mental disorder. Amongst adolescent mothers the likelihood increases to one in every two. Taking into consideration HIV, the number is likely to be more. Yet mental health is not in many HIV policies. This impacts on multiple outcomes; poor mental health creates poor MNCH outcomes for both mother and child; it can lead to poor responsive caregiving and developmental delays in the child; and it can limit livelihood opportunities.



We must integrate mental health into a broader programme of support to adolescent mothers and their children including HIV, sexual and reproductive health and rights programmes, health, nutrition and responsive caregiving. Whilst there is evidence on the important impact this can have on general adolescent populations, there is not much evidence specifically for HIV-affected adolescent mothers.

Helping Adolescents Thrive (12) is a new set of guidelines from WHO on improving mental health amongst adolescents. Our review found 17 studies on adolescent mothers and mental health, but none of these were from low and middle-income countries. We also only found three studies on what mental health interventions work for adolescents living with HIV. There is a critical evidence gap in this regard. Much like any biomedical interventions, we need to be precise in how we address mental health.

Kate Powis, Harvard University —

Preventing the mother-to-child transmission of HIV is being taken up, and vertical transmission has been reduced from 200 000 to 160 000. There are an estimated 1.2 million HIV-exposed uninfected children, 90% of them in sub-Saharan Africa. The number of HIV-exposed uninfected children is growing and will steadily increase. In some countries, HIV-exposed uninfected children account for 20% of the children. Many data show that HIV-exposed uninfected children are more at risk of being born preterm and are more likely to experience infectious morbidity and mortality. Evidence is also emerging that exposure to HIV can increase the risk of neurodevelopmental delays. There is very little research on the HIV-exposed uninfected children of adolescent mothers in particular. One small cohort Kate has worked on suggests much higher morbidity among the HIV-exposed uninfected children of mothers who themselves were born with HIV (as opposed to being infected later on).



The first 1000 days – from conception to age three years – are a vital window to improve early childhood development outcomes. We need to understand what is stopping adolescent mothers from accessing antenatal care rather than waiting to access services later on. We need to be in prevention mode – preventing HIV and unplanned pregnancy. But we cannot stigmatize those that do. We need to encourage them into care. And balance efforts to encourage adolescents back to school, with support for breastfeeding. This requires a family-centred approach to programming. The grandmother may take on a key role – however, she herself needs to be equipped with nurturing care capacity.

Martina Penazzato, WHO —

The Nurturing Care Framework provides a structure for addressing the key components of holistic support for unborn and young children. In July 2019, WHO hosted a meeting on how the HIV response can offer an opportunity to deliver the Nurturing Care Framework in many contexts where it is needed. We thought through how to integrate nurturing care with HIV. HIV brings additional nurturing care challenges; but it also provides additional entry points for support via the HIV response. Every point of contact with the health system is an opportunity to deliver nurturing care interventions. It is also critical that we not make HIV-exposed uninfected children different to others and that the way we provide services is not unique to them. We must scale up early childhood development services through the Nurturing Care Framework in a way that acknowledges the particular vulnerability of HIV-affected children without ostracizing them. And we should give priority to delivering the Nurturing Care Framework among those at greatest risk by, for example, providing parenting education and nutritional support to adolescent mothers attending antenatal and postnatal clinics. Botswana, Ghana, Kenya and other countries are showing us the way in delivering the Nurturing Care Framework. We are doing a lot more differentiated service delivery in a targeted way. There is an opportunity to integrate the Nurturing Care Framework – both from the HIV side and from the early childhood development side. Part of making this happen is about sharing information better between sectors, while also teasing out what works from the country experience and sharing it with other contexts.



5. CONSOLIDATING KEY ADVOCACY MESSAGES AND RECOMMENDATIONS

This was a small group exercise, chaired by **Luann Hatane of PATA (Pediatric-Adolescent Treatment Africa)** to reflect on and refine further the advocacy recommendations proposed earlier in the day. Participants were split into three groups focusing on advocacy towards government, donors and civil society and asked to identify their priority advocacy asks. We noted the advocacy recommendations (3) already developed by the Coalition and asked participants to reflect on these in their own discussions. See the summary section. Below were the key recommendations to donors, governments and civil society.



Advocating to donors (Chair, Catherine Connor of Elizabeth Glaser Pediatric AIDS Foundation; rapporteur, Corinna Csaky of the Coalition) —

This group discussed advocacy towards private trusts and foundations, bilateral and multilateral donors from not just the HIV sector, but also those interested in, for example, education, gender, health, hunger, equity, communities, rights and multisectoral integration itself.

We acknowledged that, in advocating for adolescent mothers and their children, we do want to take resources from other vulnerable groups or other necessary work. We also noted that donors' programmes and strategies change over time and that there would inevitably be a need to defend funding for this population with each new strategy. We must also be mindful of the pressures that donors are under: for example, to fund innovation and to show results within a certain time frame. They may also be limited to showing impact in one area, which may not fit easily with the holistic approach we are seeking. To justify their investments, they require a costed plan with a time frame and definable impact. We will need to produce this as part of our advocacy strategy.

We acknowledged that many of the qualities of interventions we are seeking – such as rights-based, multisectoral, community-led and sustainable – are often already promoted within standard donor requirements. Nevertheless, these qualities are not evident on the ground. To address these, we will need to pinpoint more specific indicators that obligate meaningful enactment.

Advocacy recommendations

- Give priority to adolescent mothers and their children in donor strategies, programmes and indicators across a range of outcomes; encourage all grant applicants to consider what role this population has in its proposed programme; and support further research, communication and youth-led campaigns targeting this population.
- Make funding more accessible to small community-based organizations – create special funding structures for them that enable greater flexibility in allocating funding.
- Allocate a percentage of all investment towards indirect resources, to enable grant recipients to build the system around multisectoral integration and to put money aside for when the intervention transitions to being locally resourced.
- Make multisectoral collaboration a donor requirement, for example, in funding applications and progress indicators.
- Champion these recommendations among other donors and key stakeholders.

Advocating to governments (Chair, Chewe Luo, UNICEF; rapporteur Sarah Bowler, Drexel University) —

Advocacy recommendations

- Champion an enabling environment for HIV-affected adolescent mothers and their children with strong laws and policies that promote and protect their human rights and tackle harmful norms, practices, stigma and discrimination associated with them

- Provide adolescent mothers and their children a comprehensive package of integrated services and support, backed up with strong laws and policies. This should combine support on HIV and health, education, justice and social protection. And include, for example, support to adolescent mothers to return to school; providing all children with comprehensive sexuality education; and tackling harmful traditional practices and social norms. Support should be delivered in various settings across sectors and go beyond the health centre; be friendly and welcoming; and be carried out in partnership with adolescents.
- Improve the coordination of support and information on adolescent mothers and their children – both between sectors and between clinics and communities. This includes sharing data more systematically between the stakeholders.
- Disaggregate data between 15–19 and 20–24 years old and use this to increase visibility, improve programming and strengthen accountability for adolescent mothers. This includes, for example, a scorecard, national index and other tools. It may require changes to ethical guidance and consent laws to enable adolescents to report on their needs more effectively.

This group also highlighted several other priorities, many of which are implicit in the recommendations given priority above:

- putting adolescent parents at the centre and coordinating services around them;
- improving and implementing policies that:
 - support pregnant and adolescent mothers to return to school, which requires teacher training to reduce stigma; flexibility and support structures; and support to ensure schools are adolescent mother friendly;
 - provide all children with school health services, including comprehensive sexuality education;
 - obligate governments to include adolescents in policies and decision-making;
 - protect and realize the rights of adolescents, including around early marriage, female genital mutilation and other harmful cultural practices;
 - review ethics and consent issues so that research with and on adolescents can be more accurate and involve them in the process and make recommendations, since some adolescents who are pregnant may not be able to consent;
 - tap into adolescent peer networks;
 - review the stigma reduction in health services work of UN Women; and
 - review existing service data to identify gaps.

Civil Society Group (Chair, Nicola Willis, Africaid Zvandiri; rapporteur, Elona Toska, Cape Town University) —

Advocacy recommendations

- Support the meaningful participation of adolescents and young people at every stage. This includes, supporting them to design and disseminate communication strategies and activities led by adolescents and to monitor and report on the implementation and quality of services and policies.
- Promote the design and implementation of multisectoral approaches around HIV-affected adolescent mothers and their children. This includes reviewing current programmes, strategies and policies and identifying gaps and priorities for each context.
- Champion collaboration, learning and sharing between sectors, stakeholders and settings on HIV-affected adolescent mothers and their children.
- Tackle stigma surrounding HIV-affected adolescent mothers and their children at all levels and in all forms, including using the People Living with HIV Stigma Index as a tool for engaging faith-based organizations.

The group also noted that stigma should be mainstreamed throughout all this work and that the People Living with HIV Stigma Index is a useful tool in this regard.

6. CLOSING REMARKS AND NEXT STEPS

Quarraisha Abdool Karim, CAPRISA, UNAIDS Collaborating Centre for HIV Research and Policy —

Primary prevention of HIV remains our greatest challenge in sub-Saharan Africa, especially for adolescent girls. We must acknowledge the gains made in preventing the mother-to-child transmission of HIV and progress towards the 90–90–90 targets. We all know that our progress can be so easily reversed and we need to sustain these efforts. We are at a convergence of horizontal and vertical transmission. We must maintain these viral suppression rates. This convergence and building on the success of treatment and preventing the mother-to-child transmission of HIV is centrally important and a mutually beneficial partnership. The process for setting 2025 targets is already underway. The question is not what we need but rather how we do it. Integrated structures and social enablers are two key themes that have been discussed. Measurement is also key for accountability.

The diversity of expertise in this learning session is very rich. And it will take special planning and facilitation for people across sectors to speak openly and collaborate. Some of us have been talking about how to use HIV and its successes and bringing in maternal, newborn and child health and early childhood development, mental health and a multisectoral response. These are all issues beyond HIV and health. They include food security, economic empowerment and stigma and discrimination. They indicate rights, respect, choice and dignity – all of which are essential for societal transformation.

Adolescents and civil society and how we engage them are also important: as meaningful partners; with accountability tools and structures; and as service providers.

The root cause of women's vulnerabilities is gender-powered disparities. Who determines these disparities is largely up to men leading countries and institutions. This is a transformation agenda. And if we can enable and empower young people, who are the majority population in Africa, we put ourselves on a different trajectory in sub-Saharan Africa.

Lisa Bohmer, Conrad N. Hilton Foundation and Co-Chair of the Coalition —

We have come some way today to address the multi-sectoral support that the young mothers asked for in their videos this morning. The human capital perspective is important and the intergenerational cycle is a powerful tool with governments. The NCF is gathering momentum and WHO is about to release new guidelines on it that includes maternal mental health. Thank you to WHO for hosting this meeting; to Wole Ameyan at WHO and Corinna Csaky at the Coalition for putting it together; and to Sarah Bowler from Drexel University for helping to minute it.

Meg Doherty, WHO —

WHO is in a period of transformation and being asked to reflect on its impact and integration. The goal of our Director-General is to break down our silos. This is a good example of an effort that has brought many different WHO departments together and with other partners. In thinking about the HIV targets, it is going to get harder now; the more straightforward work has been done. Now the challenge is to find new ways to identify people and serve their holistic needs through integrated approaches. WHO has a new working group for women living with HIV that includes some young people. They are there to ensure that our guidelines and implementation tools work effectively for people like them. The work is not done, and WHO is committed to seeing this through.

The following next steps were agreed —

- A meeting report will be circulated for review.
- Global dialogue will continue with stakeholders at this learning session, including through webinars.
- It is planned to continue this advocacy at major upcoming conferences.
- An advocacy brief will be developed from the outputs of this learning session.
- Produce a scorecard tracking the extent to which major donors give priority to children and adolescents affected by HIV and AIDS and holistic support to them.
- Link this area of work with other established working groups including the WHO women living with HIV working group and others similar working groups.

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All presentations and key documents referenced in this report are available at <https://childrenandhiv.org/resource-types/adolescent-mothers-affected-by-hiv-and-their-children>.

ANNEX 1. AGENDA

A Learning Session on HIV-affected Adolescent Mothers and their Children in Sub-Saharan Africa

13 December 2019, 08.45–16.00h

WHO, D-Building (Room 46025), Geneva, Switzerland

Time	Agenda	Presenter
08:45	Registration and refreshments	
09:00	Welcome by co-chairs, The Coalition for Children affected by AIDS, WHO and PMNCH	Dr Meg Doherty, WHO; and Lisa Bohmer, the Conrad N. Hilton Foundation and Chair of the Coalition for Children affected by AIDS
09.15	Section 1: Overview	Panel presentation followed by Q&A Chaired Dr Meg Doherty, WHO; and Lisa Bohmer, the Conrad N. Hilton Foundation and Chair of the Coalition for Children affected by AIDS
	Comments from adolescent mothers	Video of adolescent mothers
	Why are HIV-affected adolescent mothers and their children central to global strategies, frameworks and norms?	WHO; Gretchen Bachman, USAID; Catherine Bilger, UNAIDS
	What is the evidence telling us? <ul style="list-style-type: none"> Read out from Stay Free evidence sharing on HIV prevention amongst adolescent mothers, hosted by EGPAF Results of an evidence review by the University College London and the Universities of Cape Town and Stellenbosch: What are the outcomes for adolescent mothers and their children across SDG and HIV indicators? And what are the implications for the attainment of development and HIV goals? 	Chip Lyons, EGPAF and Lorraine Sherr, University College London
	The Programming Landscape: What is being done? <ul style="list-style-type: none"> What development programmes currently target HIV-affected adolescent mothers and their children? To what extent are international donors and policy makers supporting work on the ground? 	Chewe Luo, Unicef & Laurie Gulaid, Unicef ESARO
10.30	Section 2: What Needs to Change – Tackling exclusion	'Fishbowl' Discussion Chaired by Wole Ameyan, WHO
	Improving the Human Rights and Legal Environment	Quarraisha Abdool Karim, UNAIDS Collaborating Centre for HIV Research & Policy (CAPRISA)
	What role can men and boys play and how best to support them?	Lycias Zembe, UNAIDS
	Tackling poverty and inequality amongst HIV-affected Adolescent Mothers	Karen Austrian, The Population Council
	Strengthening sexual and reproductive health rights amongst HIV-affected Adolescents	Dr. Venkatraman Chandra-Mouli, WHO

11:30	Photo and break	
11.45	Section 3: What Needs to Change – Supporting Nurturing Care	'Fishbowl' Discussion Chaired by Lynette Mudekunye, REPSI
	Mobilising governments, policy makers and civil society around Nurturing Care	Lynette Okengo, African Early Childhood Development Network
	Supporting HIV-affected adolescent mothers to provide nurturing care	Monica Ogutto, KMET
	Building mental resilience amongst HIV-affected adolescent mothers	Tarun Dua, WHO
	HIV exposed uninfected children – what can we say about those of adolescent mothers in particular?	Kate Powis, Harvard University
	Remarks on opportunities for integrating CHEU into the nurturing care framework	Martina Penazzato, WHO
13.00	Lunch	
14:00	Section 4: Consolidating Key Advocacy Recommendations	Small groups exercise chaired by Luann Hatane, PATA and Co-Chair of the Coalition for Children affected by AIDS
	<ul style="list-style-type: none"> Participants break up into small groups to refine and rank their priority recommendations. Plenary reflection and consolidation Break incorporated	All
15:30	Final reflections	Quarraisha Abdool Karim, UNAIDS Collaborating Centre for HIV Research & Policy (CAPRISA)
15:45	Next steps and closing remarks	Dr Meg Doherty, WHO and Lisa Bohmer, the Conrad N. Hilton Foundation and Chair of the Coalition for Children affected by AIDS
16.00	End	

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Bachman	Gretchen	United States Agency for International Development	United States
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Bilger	Catherine	UNAIDS	Switzerland
Bohmer	Lisa	Conrad N. Hilton Foundation	United States
Bowler	Sarah	Drexel University	United States
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