

# TIME TO STEP-UP: PRIORITIZE CHILDREN, ADOLESCENTS, FAMILIES AND CARERS AFFECTED BY AIDS IN EASTERN AND SOUTHERN AFRICA

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**Ending the HIV pandemic is possible, but to do so, we must act quickly and recognize that the needs of children—the most vulnerable among us and unable to advocate on their own behalf—include but go beyond ending the spread of HIV and finding a cure. For children, urgent steps are required including: better integrating strategies to reach this population into regional and national plans; providing the care and support needed to ensure optimal development; and scaling up treatment, prevention and access to services—for children and their carers.**

In eastern and southern Africa — the regions of the world with the highest levels of HIV prevalence — meeting the needs of children and adolescents, as well as their families and others who help to care for them, is a critical step we must take in order to defeat the disease. As discussions about national commitments to the Sustainable Development Goals continue, it is imperative that these populations receive greater attention.

Even if a child receives the necessary treatment, the long-term effects of the disease impact their quality of life. And the impact of HIV and AIDS is not limited only to those children who have contracted it themselves. Those whose parents have the disease, or who have lost a family member to it, also experience long-term effects. Studies show that children infected with — and affected by — HIV experience cognitive delays and school risks.<sup>1</sup> These children also face stigma, non-adherence, trauma, depression and behavioural problems from a combination of direct viral effects as well as indirect family and parenting effects.<sup>2</sup>

# The Impact of HIV and AIDS on Children

Though great progress has been made in the fight against the disease globally, advancements for children are lagging behind:

As of 2013, an estimated 17.7 million children worldwide had lost one or both parents to AIDS.<sup>3</sup>

In Eastern and Southern Africa 40 – 60 percent of children orphaned by AIDS are cared for by older people, mainly older women.<sup>4</sup>

In 2013, only 42 percent of HIV-exposed infants received early diagnostic services within the first two months of life.<sup>5</sup>

Only 24 percent of all children living with HIV received antiretroviral treatment.<sup>6</sup>

Children with HIV have cognitive delays and their school attendance and performance is affected. HIV-exposed but uninfected children also perform less well than unaffected children on cognitive measures.<sup>7</sup>

240,000 children globally became newly infected with HIV in 2013, equivalent to one new infection every two minutes.<sup>9</sup>

An estimated 190,000 children aged 0–14 died of AIDS-related causes in 2013 due to lack of treatment.<sup>8</sup>

In 2013, 3.2 million children under the age of 15 were living with HIV, 210,000 in sub-Saharan Africa alone.<sup>10</sup>

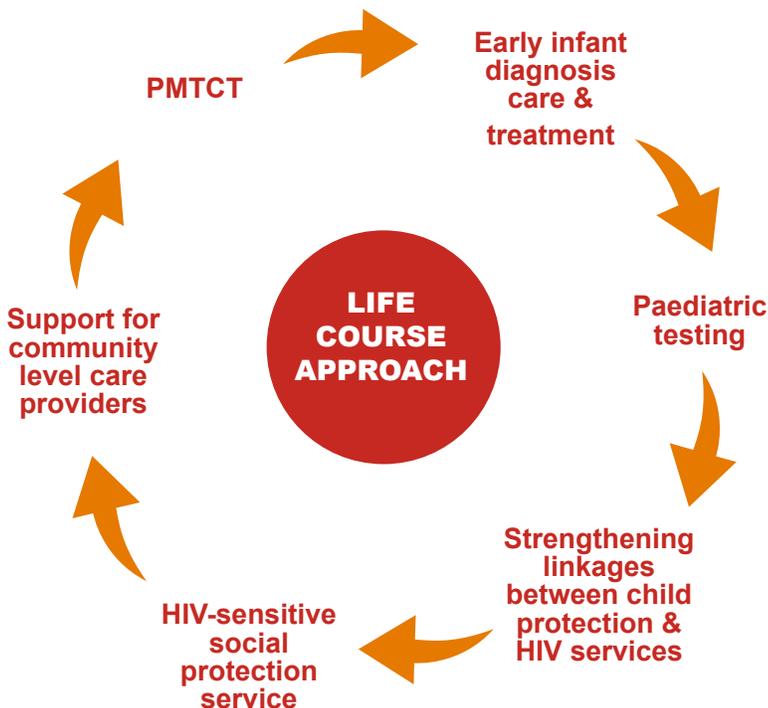
## OPPORTUNITIES AND CHALLENGES

Declarations made at the global and regional levels provide a strong foundation for continued policy discussions related to children, adolescents, and those who care for them affected by HIV and AIDS. See Appendix A for detailed commitments.

Unfortunately, these global and regional commitments have rarely translated into national level action. Though efforts are underway to address this crucial missed step, the fact remains that governments must give greater priority to integrating — and, most importantly, implementing — commitments to alleviate the adverse effects of HIV and AIDS on children, adolescents, families and carers.

## ACTION STEPS

Following are the critical action steps needed to provide children, adolescents and carers affected by HIV and AIDS in eastern and southern Africa with the focused attention required to turn the tide on the disease.



2010

HIV and AIDS Strategic Framework



2011

Political Declaration on HIV and AIDS



2012

EAC HIV and AIDS Prevention and Management Act

2013



Abuja Actions Towards the Elimination of HIV & AIDS, TB & Malaria in Africa by 2030



2015

EAC AIDS/SYI & TB Multisectoral Strategic Plan and Implementation Framework

## Scale-up Access to PMTCT Services

Though progress related to access of prevention-of-mother-to-child-transmission (PMTCT) services has been made in some countries, it has stalled and even declined in others. Between 2012 and 2013, the percentage of pregnant women living with HIV who received antiretroviral medicines rose only marginally from 64 percent to 68 percent.<sup>11</sup> At this rate, the PMTCT target put forth by *The Global Plan Towards the Elimination of New HIV Infections Among Children by 2015 and Keeping Their Mothers Alive (the Global Plan)* at the 2011 United Nations General Assembly High Level Meeting on AIDS — reducing new infections among children by 90 percent by 2015 — will not be reached. Renewed efforts will be needed to achieve the Plan's targets, especially in countries making the slowest progress.

### KEY ACTIONS REQUIRED

- **Treatment must be provided to the 30 percent of pregnant women living with HIV who are not receiving ARV treatment to prevent vertical transmission.**
- **Governments and the international community must agree to extend the Global Plan and set ambitious targets for ending new HIV infections among children and keeping their mothers alive and healthy.**

Studies indicate that up to 51 percent of infants who test positive for HIV in eastern and southern Africa never receive their results.<sup>12</sup> New diagnostic tools have the potential to overcome some of these challenges. Two early infant diagnosis point-of-care tests will shortly enter the market which could significantly reduce the need for remote testing at centralized labs and largely eliminate turnaround times, helping minimize early loss to follow-up (see Appendix B for additional details). Ultimately, a mix of centralized laboratories and point-of-care tools is needed to ensure timely diagnosis of children in diverse, resource-limited settings.

- **HIV testing must be prioritized as soon as possible after infants of women living with HIV are born, as peak mortality for infants living with HIV occurs at six to eight weeks. Testing should be repeated throughout the breastfeeding period when the risk of transmission is still substantial.**
- **Point-of-care should be included in national paediatric diagnostic scale-up plans and introduced as soon as possible, especially into remote facilities.**
- **Early infant diagnosis should use all possible child survival entry points — integrated community case management for sick children, immunization, and other child care point such as in-patient departments — as they appear to be more effective than only PMTCT platforms.**

## **Scale-up Paediatric Testing (Early Infant Diagnosis)**

**KEY  
ACTIONS  
REQUIRED**

## Increasing Treatment Access and Reducing Loss to Follow-up

Research has shown that mortality in children diagnosed with HIV can be reduced by 67 percent by using cotrimoxazole – an antibiotic – as prophylaxis. However coverage in eastern and southern Africa is only 47 percent.<sup>13</sup>

Children with HIV early antiretroviral trial interim results<sup>14</sup> show that early antiretroviral therapy (ART) in HIV-infected infants aged 6–12 weeks reduces all-cause mortality by 76 percent and HIV disease progression by 75 percent. However, access to paediatric ART is still at low levels and treatment coverage is exceptionally low in Africa. In sub-Saharan Africa, and West and Central Africa only 22 percent and 10 percent of children living with HIV obtained antiretroviral treatment in 2013.

In addition, in a pooled analysis of results from 16 paediatric HIV treatment programmes in sub-Saharan Africa, substantial loss to follow-up was found. Fifty-one percent of children who were enrolled in HIV treatment before their first birthday were lost to follow-up within 24 months.<sup>15</sup>

Over 90 percent and 76 percent of children with HIV in sub-Saharan Africa and globally respectively suffered from pain caused by symptoms related to HIV.

### KEY ACTIONS REQUIRED

- **Ensure that clinical trials for new antiretroviral medicines focus on children and pregnant women.**
- **Make greater use of maternal and child health services as an entry point to paediatric HIV treatment and care and ensure that they partner effectively with local communities.**
- **Political leadership should commit to ensuring that all children living with HIV are initiated on treatment, including cotrimoxazole prophylaxis, within six weeks of birth.**
- **Use available technology — such as digital medical records and mobile phone communication — to track children on ART.**
- **Develop patient information systems where mothers and infants are followed through as a pair rather than separately.**
- **Palliative care should be given alongside treatment to ensure that pain and other distressing symptoms such as dyspnoea, adverse effects of drugs, wasting and other debilitating symptoms — including psychological issues — are adequately controlled.**

The potential for existing social protection programmes to contribute to a comprehensive HIV response is increasingly recognized. Social protection measures, therefore, need to be HIV-sensitive, including children, adolescents, families and carers who are at risk of infection, living with HIV, or susceptible to its consequences. HIV-sensitive social protection (HSSP) measures — such as social assistance and social insurance, home-based care, education, and equity and rights-based interventions — can reduce vulnerability to infection, improve and extend the lives of people living with HIV and support individuals and households. The positive impact of these measures on children and adolescents is well recognized.

Though all components of HSSP are crucial, financial protection and cash transfers help meet basic needs and enable access to health and social services. There is growing evidence that cash transfers, in particular to girls and young women, have the potential to prevent HIV, especially sexual transmission of the disease, in certain contexts, by influencing underlying structural conditions, which, in turn, shape sexual behaviour and risk of HIV infection.<sup>16</sup>

In addition, adding on care and support interventions — making it “cash plus care” — may have a greater influence than cash alone. Efforts including positive parenting and teacher social support have been shown to greatly decrease the incidence of adolescent risk behaviour for both girls and boys.<sup>17</sup>

- **Scale-up cash transfer programmes for poor households, including those affected by HIV and AIDS.**
- **Implement integrated cash plus care interventions, such as positive parenting, school counselling, and food gardens.**
- **Increase the awareness and effectiveness of health and social service providers to the severe impacts of HIV on children, adolescents, families/carers.**
- **Provide information to families/carers on how to access HIV services and social entitlements, including psychosocial support for children/adolescents under their care.**
- **Ensure adolescents have access to HIV sensitive social protection interventions, particularly cash transfers, care and psychosocial support.**
- **Strengthen the legal protection of children, adolescents, families and carers pertaining to land and its inheritance – including by supporting access to paralegal and legal service and by providing information on human rights.**

## **Provide HIV-Sensitive Social Protection Services**

**KEY  
ACTIONS  
REQUIRED**

## Invest in the Early Years of Children Living with HIV

While diagnosis, treatment and social protection are critical, there is irrefutable evidence that a supportive early childhood environment is also imperative if children are to experience optimal cognitive, physical, emotional and social development. Though children are resilient and often can withstand pressure, unrelenting, multiple traumas become increasingly difficult to overcome.<sup>18</sup>

Negative influences during early childhood can be irremediable. For example, HIV and AIDS can cause delays in the development of physical and intellectual abilities. In addition, the experience of having a chronic illness can affect a child's sense of self. Furthermore, emerging evidence suggests that HIV-negative children whose mothers are HIV-positive fare worse than other children. Possible causes for this include the effects of ARVs in utero as well as the effects of parental stressors on the child.<sup>19</sup>

Every human being is entitled to a positive early childhood. An early, integrated approach to achieving this goal is more efficient, more cost-effective and more productive for everyone in the long-run.

### KEY ACTIONS REQUIRED

- **Ensure that children living with HIV receive early integrated services to improve their well-being and to ensure optimal development.**
- **Create a comprehensive package of services for early childhood development that takes into consideration children living with HIV.**
- **Political leadership should invest resources for the implementation of early integrated interventions that benefit children living with HIV.**
- **Ensure that mechanisms are in place to reduce stigma and discrimination barriers to early years services.**

## Strengthen Linkages between Child Protection and HIV Services

In sub-Saharan Africa, children orphaned by HIV and those living with HIV-positive care-givers face an increased risk of physical and emotional abuse. They experience greater stigma and bullying than their peers and have higher rates of transactional sex, increased unsafe sexual activity and/or experience sexual abuse.<sup>20</sup> Childhood sexual abuse is linked to higher rates of sexual exploitation and other HIV risks (e.g. earlier initiation into injecting drug use, sex work and living on the streets). There is a direct link between childhood sexual, emotional and physical abuse and HIV infection in later life for both women and men in high prevalence areas.

Children orphaned by HIV are twice as likely as non-orphans to be infected. Their caregivers have higher rates of depression than other caregivers in sub-Saharan Africa, leading to increased mental health and behavioral problems in the children.

- **Ensure that HIV and child protection are explicitly linked in one national policy. For example, using the development of the national policy frameworks for children (e.g. the National Children's Plan, Vulnerable Children's Strategy or National AIDS Strategy) to highlight the connections between HIV, economic, and child protection vulnerabilities.**
- **Guidelines and standards on HIV and child protection must include a focus on understanding and addressing HIV-related stigma and discrimination as experienced by children and adolescents.**
- **Children, adolescents and young people — especially those living with HIV — must be included in all aspects of HIV programming to help reduce stigma and discrimination and improve child protection, mental health and psychosocial well-being outcomes.**
- **Invest in a strong case-management system that links HIV, health care, economic strengthening/social protection and child protection. This will improve paediatric testing and treatment outcomes and support HIV-affected children and families/carers that are at risk of harm.**



**KEY  
ACTIONS  
REQUIRED**

## Intensify HIV Prevention and Treatment for Adolescents

There are 1.4 million adolescents (between the ages of 10 and 19) living with HIV in eastern and southern Africa; this is the only age group in which HIV infections have been increasing. HIV is the highest cause of death among adolescents in Africa.<sup>21</sup>

Treatment adherence presents a significant challenge for adolescents living with HIV whether they acquired it vertically or horizontally. Adolescence is a period of social, emotional and physical transition that can intensify the possibility of non-adherence. Stigma and discrimination makes matters worse.

### KEY ACTIONS REQUIRED

- **Strengthen the inclusion of adolescent voices in the provision of HIV services and ensure that they are fully involved in designing, implementing and monitoring programmes intended to meet their needs.**
- **Prioritize the implementation of adolescent-friendly comprehensive sexual and reproductive health and HIV services.**
- **Address abuse, violence, and stigma and discrimination faced by adolescents.**

## Strengthen Support for Primary Caregivers and Community Level Care Providers

Primary level care to vulnerable children, including those orphaned by AIDS, is provided by a variety of relatives including parents, grandparents, siblings, aunts and uncles. Older people, particularly grandmothers, are estimated to provide at least 40-60 percent of the care.<sup>22</sup> Unfortunately, older women are especially challenged to assume this role: they lack regular income support and are food insecure; the time given to caring reduces their ability to undertake income generating activities; and they struggle to ensure their grandchildren's access to health care and education and to provide parental and psychosocial support.

Primary care providers need to be reached at the community level, through home-based care providers and community health workers. In addition, they must be given access to HIV sensitive social protection and livelihood interventions. Though lack of data and evidence on the scale, nature and needs of primary and community level care providers severely restricts the development of policies, strategies and interventions, governments are finally recognizing that this population needs to be remunerated and supported. For example, the Zimbabwe Ministry of Health approved a "Carers Policy," calling for the compensation of community caregivers in kind or cash. This policy is also being considered by the Malawi Ministry of Health. Tanzania has established a home-based care coordinator cadre at the district level with plans for further expansion. The Government of Kenya provides token remuneration to community health workers as recognition for the valuable primary health care and HIV services they provide. Each of these examples provide a path forward for other countries evaluating similar approaches.

- **Determine the nature, scale and needs of those providing crucial care for vulnerable children, particularly those orphaned by AIDS.**
- **Recognize the critical role of these caregivers in continental, regional and national health, HIV and AIDS, social protection and related policies, strategic plans and guidelines.**
- **Give priority to caregivers who are particularly vulnerable (e.g. older and child carers).**
- **Replicate and scale existing policy initiatives that provide support and remuneration to community level care providers.**
- **Strengthen the voices of caregivers — including older carers, child carers and parents — on the type of support that is most crucial to them.**

**KEY  
ACTIONS  
REQUIRED**

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## **CONCLUSION**

Children and adolescents affected by AIDS — as well as those who care for them — must be prioritized in post-2015 development discussions. As consultations take place leading up to the U.N. High Level Meeting on HIV in 2016, this vulnerable population must receive increased attention. Most importantly, key action steps must be implemented to ensure the needs of this group are met. In so doing, we will ensure that the needs of children become an integral consideration in the effort to end this pandemic.

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## 2010 – 2015 SADC HIV and AIDS Strategic Framework

Harmonised approaches and guidelines on social protection to reduce vulnerability of OVCY and carers, particularly the elderly, to the impact of HIV and AIDS

- Develop regional guidelines and strategies on priority issues for OVC and carers incl. psychosocial support, economic empowerment, youth leadership
- Facilitate integration of OVCY and carer issues in SADC and Member States development, poverty and sector plans (e.g. PRSPS, education, welfare)

## 2011 Political Declaration on HIV and AIDS: Intensifying our Efforts to Eliminate HIV and AIDS

**Paragraph 68.** Commit to develop and implement strategies to improve infant HIV diagnosis, including through access to diagnostics at point-of-care, significantly increase and improve access to treatment for children and adolescents living with HIV, including access to prophylaxis and treatments for opportunistic infections, as well as increased support to children and adolescents through increased financial, social and moral support for their parents, families and legal guardians, and promote a smooth transition from paediatric to young adult treatment and related support and services

**Paragraph 82.** Commit to strengthen national social and child protection systems and care and support programmes for children, in particular for the girl child, and adolescents affected by and vulnerable to HIV, as well as their families and caregivers, including through the provision of equal opportunities to support the development to full potential of orphans and other children affected by and living with HIV, especially through equal access to education, the creation of safe and non-discriminatory learning environments, supportive legal systems and protections, including civil registration systems, and provision of comprehensive information and support to children and their families and caregivers, especially age-appropriate HIV information to assist children living with HIV as they transition through adolescence, consistent with their evolving capacities;

## APPENDIX A Details on global and regional declarations prioritizing children, adolescents, families and carers affected by AIDS

**APPENDIX A**  
**Details on global and regional declarations prioritizing children, adolescents, families and carers affected by AIDS**

**2012 East African Community (EAC) HIV and AIDS Prevention and Management Act**

**Section 34:** Children living with or affected by HIV

(5) The Government shall take specific measures to ensure the protection and best interests of children living with or affected by HIV against all forms of abuse, violence and exploitation including:

(b) Adoption of measures to safeguard the inheritance and property rights for such children;

**Section 44:** Support of community and home-based caregivers

(a) Develop a framework for the regulation and support of community and home-based programmes to ensure the respect of human rights and the provision of quality services.

**2013 “Abuja Actions Towards the Elimination of HIV & AIDS, TB & Malaria in Africa by 2030” - Declaration of the Special Summit of African Union on HIV/AIDS, TB & Malaria**

**Paragraph 7 iv.** Implement effective and targeted poverty elimination strategies and social protection programmes that integrate HIV/AIDS, TB and Malaria for all, particularly the vulnerable populations;

**Paragraph 7 ix.** Accelerate HIV prevention programmes using a combination of effective evidence-based prevention, particularly for young people, women, girls and other vulnerable populations, to successfully reduce the number of new HIV infections towards the goal of zero new infection by 2030;

**Paragraph 7 x.** Eliminate mother-to-child transmission of HIV while keeping mothers alive and addressing the disproportionate impact of the three diseases on children, girls and women;

**Paragraph 7 xiii.** Take deliberate and bold action to accelerate children and adolescent access to Anti-Retroviral (ARV) treatment within the continuum of care, support the Treatment 2015 campaign championed by UNAIDS and WHO and invite pharmaceutical industries to explore possibilities of extending the expiration date of the ARVs;

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Vulnerable groups in infant and young children, orphans and other vulnerable children and adolescents. Strengthen capacities of NGOs/CBOs/FBOs to advocate for inclusion of interventions that reduce the vulnerability of children of vulnerable and key populations to HIV infection by retaining them in schools, as well as providing post-school education, work and other opportunities.

## **APPENDIX B Additional Background on the Scale-up of Paediatric Testing (Early Infant Diagnosis)**

Although development of the dried blood spot specimen collection technique for early infant diagnosis was a step forward, the necessary reliance on centralized laboratories for virological testing is associated with increased transport costs and substantial turnaround time for results. Studies indicate that up to 51% of infants who test positive never receive their test results. New diagnostic tools have the potential to overcome some of the challenges associated with the current laboratory-based DNA tests. Two early infant diagnosis point-of-care tests will shortly enter the market which could potentially remove the need to send dried blood spot specimens for remote testing at centralized labs, largely eliminating turnaround times and helping minimize early loss to follow-up. Ultimately, a mix of centralized laboratories and point-of-care tools is likely to be needed to ensure timely diagnosis of children living with HIV in diverse resource-limited settings. In 2013 only 42% of HIV-exposed infants received early infant diagnostic services within the first two months of life.

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