TIME TO STEP-UP:

PRIORITIZE CHILDREN, ADOLESCENTS, FAMILIES AND CARERS AFFECTED BY AIDS IN EASTERN AND SOUTHERN AFRICA

EXECUTIVE SUMMARY

JULY 2015

RATT
Eastern & Southern Africa
Regional Inter Agency Task Team on Children & AIDS

The Coalition for Children Affected by AIDS

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.[1]
- In 2013, only 42 percent of HIV-exposed infants received early diagnostic services within the first two months of life.[3]
- In Eastern and Southern Africa 40 – 60 percent of children orphaned by AIDS are cared for by older people, mainly older women.[2]
- Only 24 percent of all children living with HIV received antiretroviral treatment.[4]
- 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.[5]
- 240,000 children globally became newly infected with HIV in 2013, equivalent to one new infection every two minutes.[7]
- 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.[10]
- In 2013, 3.2 million children under the age of 15 were living with HIV, 210,000 in sub-Saharan Africa alone.[8]
- Studies indicate that up to 51% of infants who test positive never receive their test results.[9]
- An estimated 190,000 children aged 0–14 died of AIDS-related causes in 2013 due to lack of treatment.[6]

As discussions about national commitments to the Sustainable Development Goals continue, it is imperative that children and adolescents affected by HIV and AIDS — as well as those who care for them — receive greater attention.

Critical steps required for children affected by AIDS and their caregivers:

- **Prioritise the needs of children and carers in regional & national HIV strategies and plans;**
- **Scale-up access to prevention & treatment services;**
- **Provide care & support for optimal child development.**

Scale-up Access to Prevention of Mother-to-Child-Transmission Services: Renewed efforts related to access of Prevention of Mother-to-Child Transmission (PMTCT) services is needed to achieve global targets.

Access to PMTCT services has stalled in some countries and even declined in others.

KEY ACTIONS REQUIRED

- **Provide treatment for the 30 percent of pregnant women living with HIV not currently receiving ARV treatment to prevent vertical transmission.**
- **Extend the Global Plan and set ambitious targets for ending new HIV infections among children and keeping them and their mothers alive and healthy.**

Scale-up Pediatric Testing (Early Infant Diagnosis): Ensure timely diagnosis of children in diverse, resource-limited settings.

More than half of infants who test positive for HIV in eastern & southern Africa never receive their test results.

KEY ACTIONS REQUIRED

- **Prioritize HIV testing as soon as possible after infants of women living with HIV are born. Testing should be repeated throughout the breastfeeding period when the risk of transmission is still substantial.**
- **Include point-of-care into national paediatric diagnostic scale-up plans and ensure they are 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 points such as in-patient departments — as they appear to be more effective than only PMTCT platforms.**

Increasing Treatment Access and Reducing Loss to Follow-up: Scale up access to the appropriate treatment for children diagnosed with HIV and mitigate loss to follow-up.

Access to paediatric ART is still at low levels and treatment coverage is exceptionally low in Africa.

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 such as digital medical records and mobile phone communication — to track children on ART.**
- **Develop patient information systems where mothers and infants are followed as a pair rather than separately.**
- **Palliative care should be given alongside treatment to ensure that pain and other distressing symptoms are adequately controlled, including psychological issues.**

Provide HIV-Sensitive Social Protection Services: Integrate HIV-sensitive social protection programmes, including cash transfers, as part of countries' national HIV responses.

HIV-sensitive social protection interventions bolster HIV treatment, prevention, and care and support efforts, but their roll-out is far from universal.

KEY ACTIONS REQUIRED

- **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.**
- **Create awareness about the impact of HIV on children, adolescents and families/carers to health and social service providers.**
- **Provide information to families/carers on how to access HIV services and social entitlements.**
- **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 services and by providing information on human rights.**

Invest in the Early Years of Children Living with HIV: Establish the supportive environment necessary for children's optimal cognitive, physical, emotional, psychological and social development.

Investment in the early years is more cost-effective and more productive in the long run, but political and financial commitments at this critical stage in a child's life have been missing.

KEY ACTIONS REQUIRED

- **Ensure that children living with HIV receive early integrated services to improve their well-being and 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: Address the increased risk of physical and emotional abuse faced by children affected by HIV and those living with HIV-positive sick caregivers.

There is a direct link between childhood sexual, emotional and physical abuse and HIV infection in later life in high-prevalence areas.

KEY ACTIONS REQUIRED

- **HIV and child protection should be explicitly linked in one national policy framework, for example the next national policy framework for children.**
- **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.**
- **Invest in a strong case-management system linking HIV, health care, economic strengthening/social protection and child protection.**

Intensify HIV Prevention and Treatment for Adolescents: Address issues of social, emotional and physical transition and stigma impacting adolescents.

Adolescence is the only demographic in which HIV infections have been increasing in sub-Saharan Africa.

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, stigma and discrimination faced by adolescents.**

Strengthen Support for Primary Caregivers and Community Level Care Providers: Ensure that support reaches primary caregivers of children affected by AIDS with support and provide remuneration for community level care providers.

Governments are increasingly recognizing that family and community level care providers shoulder most of the burden, but are inadequately supported.

KEY ACTIONS REQUIRED

- **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-up existing policy initiatives providing support and remuneration to community level care providers.**
- **Strengthen the voices of caregivers — including older carers, child carers and parents — with respect to the type of support that is most crucial to them.**

1. UNICEF. Last modified June 2015. http://data.unicef.org/hiv-aids/care-support

2. UNICEF. "Africa's Orphaned Generation." New York. 2003. p. 16

3.UNAIDS. "Diagnostic Access Initiative to Achieve the 90-90-90 Treatment Target." 2015. p. 4. Geneva.

4. UNAIDS. "Gap Report."Geneva. 2014. p. 19

5. Sugandhi et al. "HIV-exposed infants: rethinking care for a lifelong condition" AIDS. Vol. 27 (Supplement 2), pages S187-S195. 2013

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7. UNAIDS. "Gap Report."Geneva. 2014. p. 232

8.UNAIDS. "Gap Report."Geneva. 2014. p. 17

9. McNairy, ML, Lamb, MR, Carter, RJ et al. Retention of HIV-infected children on antiretroviral treatment in HIV care and treatment programs in Kenya, Mozambique, Rwanda, and Tanzania. Acquir Immune Defic Syndr. 2013

10.Violari A, Cotton MF, Gibb DM, Babiker AG, Steyn J, et al. "Early antiretroviral therapy and mortality among HIV-infected infants." N Eng J Med 2008 359: 2233–2244

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