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No adolescent living with HIV left behind: a coalition for action

Participating organisations

Asia Pacific Network of People Living with HIV
African Young Positives
CIPHER, International AIDS Society
Desmond Tutu HIV Foundation
Global Youth Coalition on HIV/AIDS
HIV Young Leaders Fund
International Planned Parenthood Federation
Global Network of People Living with HIV
International Community of Women Living with HIV
International Civil Society Support
International Community of Women Living with HIV Zimbabwe
International HIV/AIDS Alliance
International Treatment Preparedness Coalition
Medicines Sans Frontiers
TREAT Asia
The PACT
Paediatric AIDS Treatment for Africa
Universities Allied for Essential Medicines
United Nations Joint Programme on HIV/AIDS
United Nations Educational, Scientific and Cultural Organization
United Nations Children's Fund
United Nations Population Fund
World Health Organization
Y+, the global network of young people living with HIV

Introduction

HIV is now estimated to be the number two cause of death among adolescents (10-19) globally, and the number one in Africa, at a time when HIV-related deaths are decreasing in all other age groups. [i] The poor quality of, and retention in, services for adolescents is well documented and there is an urgent need to improve service delivery. To reverse this trend, a new coalition has formed to catalyze change in the HIV response for adolescents.

The actions outlined here capitalize on collaborations among networks of people living with HIV, HIV treatment organizations, youth groups - including young people living with HIV - researchers, clinicians and global health agencies to fill some of the urgent gaps in addressing the treatment and care needs of adolescents living with HIV. In addition, it marks the starting point of efforts to address some of the structural barriers that prevent governments from fulfilling adolescents' right to health.

This document also summarizes key treatment-related issues identified by partner organizations in Cape Town, South Africa in April 2014.[ii] This is not a comprehensive agenda – but a practical tool which builds on existing work to take steps to scale up treatment and care for adolescents.[iii] The timing is critical to ensure equity in access in reaching the 2011 United Nations General Assembly Declaration of Commitment on HIV/AIDS 2015 treatment goals, contributing to the UNAIDS Treatment 2015 agenda and ensuring adolescent issues are addressed within the process to set new ambitious treatment targets for 2030.

A broad movement is essential to the success of this agenda - the participating organizations welcome new partners and encourage any group interested in collaborating to contact the coalition organizers.[1]

[1] For more information about how you and your organisation could get involved please contact: ALHIVcoalitionforaction@gmail.com

Meeting the treatment needs of Adolescents living with HIV

There are currently 2.1 million adolescents aged 10 - 19 living with HIV globally.[iv] These adolescents either acquired HIV through vertical transmission or during adolescence. Both groups of adolescents living with HIV have specific as well as overlapping needs and common challenges.

Adolescents living with HIV face major barriers in accessing treatment and care programmes, and these are often exacerbated for adolescent girls and adolescent key populations.[v] These adolescents are often denied HIV services or are unable to access them due to age- and behavior related discrimination, gender and socio-economic inequalities.

Although treatment coverage data for adolescents globally is currently unavailable – only 30 countries were able to report the number of adolescents receiving ART in the Global AIDS Response Progress Reporting System as of May 2014 – what is known paints a stark picture. Only 34 percent of children aged 0 - 14 who need treatment today in low and middle-income countries receive it – compared with 64 percent of adults eligible under WHO 2010 ART guidelines.[vi] This gap is even wider under WHO 2013 ART guidelines.[vii] Currently there are no robust estimates of adolescent treatment and care coverage as countries are not required to report uniquely for ages 10-19.

All adolescents living with HIV have a right to access HIV treatment and care. The below issues must be addressed to ensure the rights to health and dignity of adolescents living with HIV are fulfilled.

Increase access to HIV testing

HIV testing and counselling remains the critical entry point to the continuum of care for adolescents living with HIV, yet a majority are still unaware of their status. For example, survey data collected from sub-Saharan Africa indicate that only 10% of young men and 15% of young women (15–24 years) were aware of their HIV status.[viii] Legal, policy and social barriers to HIV testing – such as parental consent laws and HIV-related stigma – prevent adolescents from taking a HIV test. Convenient, appropriate and the preferred testing options for adolescents are not widely available. Countries must be encouraged to examine their parental HIV testing policies and consider lowering the age of independent consent so that more adolescents can access testing. There is also a need to expand promising practices in creating demand for HIV testing among adolescents.

Expanding treatment options for adolescents

The lack of effective, simplified and easy-to-administer paediatric formulations affect children into adolescence. Adolescents are susceptible to long-term ART side effects that complicate ART management – such as sensitivity to physical body changes, growth and nutrition. Perinatally infected adolescents are at

particularly high risk of treatment failure and HIV drug resistance due in part to sub-optimal treatment regimens constructed with a limited range of approved ARVs for paediatric formulations and poor access to viral load for early identification of treatment failure in low and middle-income countries.[ix]

All adolescents undergo a number of social, emotional and physical transitions that increase the risk of non-adherence.[x] Adolescents who were perinatally infected with HIV now survive beyond childhood and many face treatment resistance and failure of first– and in some cases second–line regimens. They also lack access to improved treatment monitoring and expanded treatment options. Yet in many countries the necessary second– and third–line regimens are not widely available or their cost renders them inaccessible.

All adolescents living with HIV need optimal drug regimens that reduce the daily pill burden and are associated with few side effects in order to increase the likelihood of continuous adherence. They should also be included in research using novel drug delivery methods such as long-acting injectable ARVs, which would improve adherence and promote retention in care, and lessen the physical and emotional effects of life-long treatment. More innovation is needed around ART regimens targeted specifically for the needs of children and adolescents. More research initiatives for long-acting ARVs and approaches to treatment sequences are needed for adolescents, since as adolescents living with HIV age they will only need more and not fewer treatment options.

Adapting health services to adolescents' needs

Adolescents living with HIV have unique needs due to the critical transition they are experiencing – including physical, cognitive and social changes – as well as their individual life circumstances.[xi] As a result, adolescents often face particular challenges with adherence to treatment – resulting from treatment fatigue, lack of treatment education, power imbalances with their health-care provider, pill burden and absent social and nutritional support in education settings. Adolescents need better adherence support and information about their treatment regimens from health service providers and their communities so that they feel motivated to take their medication and confident to assume responsibility for their own health.

Health services must become more suitable for adolescents. Providers often lack skills to work with adolescents from key populations and girls. In some contexts, weak transition processes from paediatric to adult care results in adolescents dropping out of services. In other settings where separate services are not available, children and adolescents access services alongside adults, and providers are often not trained to deal specifically with their issues. Those who acquire HIV during adolescence are often not linked to care, and those who are in pre-ART care have little incentive to regularly visit health services; as a result they may fall out of the health system. More effort is necessary to ensure adolescents are not lost to follow up.

Adolescents living with HIV also have diverse sexual and reproductive health needs; yet they often face stigma from communities and service providers for

being sexually active. Adolescents need to access essential and stigma-free sexual and reproductive health services – including knowledge about prevention options, such as male and female condoms and other contraceptives; knowledge of the impact of ART and adherence on decreased risk of onward HIV transmission, conception advice if desired; diagnosis and management of sexually transmitted infections; and comprehensive sexuality education, including skills for safe and pleasurable sex. Communities must be educated on the sexual and reproductive rights of adolescents; the concept of positive health, dignity and prevention can be used to promote the principle that HIV prevention is a shared responsibility among adolescents and their sexual partners.

Mobilizing social support

Adolescents living with HIV and their families need more information and guidance to navigate HIV disclosure. Caregivers can be supported to disclose at younger ages to perinatally infected children, which may result in better health outcomes.[xii] Adolescents often lack support around if, when, how or to whom to disclose; as a result they may be unable to assess risk and manage reactions from friends, family and sexual partners. Criminalisation of HIV non-disclosure, exposure and transmission presents a real challenge to adolescents who are rarely able to access legal services, making them less inclined to disclose and seek appropriate support for fear of legal repercussions.

Stigma and discrimination towards adolescents living with HIV from their communities and health, education and workplace settings continues to affect their health seeking behavior and well-being. Self-stigma remains a major issue for adolescents living with HIV and is compounded for adolescent key populations, who often face discrimination on account of the behaviour that makes them vulnerable to HIV, such as sex between men, as well as their HIV-positive status.

Empowering adolescents

Involving adolescents in reviewing, adopting and implementing the WHO 2013 ART guidelines in countries, service design and delivery, leading peer support groups, and crafting messaging is critical for effective programs. With regards to treatment initiation, adolescents need to understand that beginning treatment early-on in their lives is a personal choice based on their current health, an assessment of potential risks around long-term adverse effects such as toxicities and limitation of future treatment options, ability to adhere and other factors. Funding, support and partnerships can enable adolescents living with HIV at the national and community level to lead and hold their governments accountable.

Better data to improve policies and programmes

Higher-quality data and ongoing research on adolescent outcomes are urgently needed. Disaggregating and reporting data by gender, key population and age-group may reveal more about adolescent needs. More research is needed to examine adolescent-specific treatment concerns, including treatment failure and ‘loss to program’ rates among adolescents living with HIV since birth and the

number of adolescents requiring second and third-line regimens. Good quality mortality data for this age group collected through vital registration systems or other mortality monitoring systems is also needed.

While promising approaches to promote retention in care for adolescents living with HIV have been documented at the country level, these have failed to influence international guidelines due to lack of investment in monitoring and evaluation and the rigidity of evidence standards. Attention must be drawn to increasing investment in implementation science research for this population to help inform policy makers and programme managers of scalable, effective approaches. In addition, under current standards of research ethics, the inclusion of adolescents under the age of majority in studies without parental consent is challenging; many adolescents in sub-Saharan Africa are orphaned and lack guardians. Adolescents from key populations may have a legal guardian but not live at home or may be reluctant to seek their parents' consent to participate in the research as they would have to disclose sexual or other behaviors that make them vulnerable to HIV. New efforts to collect strategic information despite these challenges are critical.

Coalition priority actions

Based on the above issues, this coalition for action has prioritized four work streams to galvanize the movement to expand HIV treatment and care to ensure no adolescent living with HIV is left behind.

Strengthen the community of adolescents living with HIV and their allies to scale up advocacy for adolescent access to optimal treatment and care at all levels of the HIV response.

This coalition will:

- Undertake community-led, participatory action research as a movement building activity to reflect on the unique needs of adolescents living with HIV and identify strategies for change.
- Broker space for the meaningful participation of adolescents living with HIV, including adolescents from key populations, in policy and program design to ensure policies and services meet their needs, including on national ART committees where they exist.
- Mobilize resources for networks of young people living with HIV so that they can involve adolescents living with HIV, including key populations, in their governance and membership to adequately respond to their advocacy priorities.

Scale-up adolescent responsive services that address the continuum of care for better health outcomes.

This coalition will:

- Advocate for provider-initiated testing and counseling in medium and high burden HIV countries, to ensure vertically infected children and adolescents become aware of their status and can be linked to treatment and care.
- Make the case that the treatment needs of adolescents are unique and deserve to be a priority - due to their higher rates of estimated mortality, critical development and other transitions, as well as the benefits to individual health and secondary prevention. This includes support for the commitment made from the World Health Organization to further address adolescent-specific treatment issues in the next ARV guideline update.
- Advocate for national programs, policies and funding allocations that adequately address the treatment and care needs of adolescents, including building alliances with other HIV and youth organizations. This includes working with Country Coordinating Mechanisms, National AIDS Councils, HIV testing and/or ART planning committees and Community Advisory Boards.
- Prioritize funding and scale-up effective community approaches to support adherence, HIV management, health system navigation, disclosure and sexual and reproductive health education.

Increase optimal treatment choices for adolescents living with HIV through advancing the broader movement for access to medicines and addressing other regulatory barriers.

This coalition will:

- Mobilize around increasing the availability and accessibility of second- and third-line regimens so that adolescents living with HIV who have failed first-line treatment can access the medicines they need.
- Advocate countries to prioritize vertically infected children and adolescents for both access to viral load testing and point of care diagnostics when appropriate, given that adolescents living with HIV are especially at risk of treatment failure due to challenges with adherence due the critical developmental transition and the shift from pediatric to adult HIV care.
- Support new research and development (R&D) approaches to incentivize innovation in areas of treatment research that have been neglected by traditional R&D systems and develop medicines adolescents actually need, as well as ensure that new and emerging treatment options are rapidly scaled-up for adolescents, such as more effective third-line regimens.

Gather, analyse and use strategic information more effectively to shape programmes and policies that impact adolescents living with HIV.

This coalition will:

- Promote the reporting of age- and sex-disaggregated data, including ensuring outcomes are reported by age group in all fora - including journals, academic publications and strategic information guidelines. Gather data on adolescent mortality, retention in care, virological suppression, treatment failure, HIV drug resistance and the need for second and third-line ARV regimens – including modelling of second– and third–line ART projections for adolescents, how the timing of ART initiation impacts these issues, as well as how adolescents living with HIV are linked to non-HIV care.
- Advocate to research funding agencies, research institutions (including clinical trial networks and academic journals) and institutional review boards to:
    - Embed implementation science components in new research initiatives that address adolescent HIV priorities.
    - Promote and support community based organisations to conduct research that directly engages adolescents living with HIV to inform programme design.
    - Lower the age of consent so that adolescents can engage research on issues that affect them to an internationally recognized standard.
- Establish, maintain and actively publicise with programme managers a centralised repository for the collection and dissemination of promising programming practices that address the needs of adolescents living with HIV. Support the rigorous evaluation of promising practices before they are taken to scale.

Modes of collaborating

Addressing the diverse needs of adolescents living with HIV requires the full participation of communities, service providers, governments and international organizations. Each of the actions above requires joint efforts; as a result four working groups comprised of participating organisations are leading each priority area. A virtual workspace has been created to facilitate this collaboration. Any organisation that is also working on these issues is strongly encouraged to contact us below.

Get involved!

For more information about how you and your organisation could get involved please contact: ALHIVcoalitionforaction@gmail.com

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[i] WHO *Health for the World's Adolescents*, May 2014.

[ii] From April 16 - 17, 2014 over thirty organizations and agencies working on HIV, health and human rights gathered in Cape Town, South Africa for the meeting Galvanizing the movement to scale-up access to optimal treatment and care for adolescents living with HIV. The meeting was convened by the Global Network of People Living with HIV, International Treatment Preparedness Coalition, the Y+ network of young people living with HIV, the PACT and the United Nations Joint Programme on HIV/AIDS and focused on exploring new collaborative efforts to address the immediate inequities adolescents face in accessing HIV treatment and care. The meeting was supported by the UNAIDS Treatment initiative.

[iii] This also builds on previous work, notably the World Health Organization's *2013 HIV Testing and Counseling and HIV Care Guidelines for Adolescents* and UNICEF consultations around the service needs of adolescents living with HIV.

[iv] UNICEF *Children and AIDS Stocktaking Report*, December 2013.

[v] *Ibid*.

[vi] *Global Report: UNAIDS report on the global AIDS epidemic*, 2013

[vii] WHO *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: recommendations for public health approach*, 2013

[viii] WHO, *HIV and Adolescents: Guidance for HIV Testing and Counselling and Care for Adolescents Living with HIV*, 2013.

[ix] Sohn, Annette and Hazra, R. *The changing epidemiology of the global paediatric HIV epidemic: keeping track of perinatally HIV-infected adolescents*, Journal of the International AIDS Society, June 2013.

[x] APN+, *Lost in Transitions: the needs of adolescents living with HIV in Asia Pacific*, 2013.

[xi] According to the World Health Organization, adolescence "represents one of the critical transitions in the life span and is characterized by a tremendous pace in growth and change that is second only to that of infancy." Source: http://www.who.int/maternal_child_adolescent/topics/adolescence/dev/en/

[xii] APN+, *Lost in Transitions: the needs of adolescents living with HIV in Asia Pacific*, 2013