



# PEDIATRIC ADVOCACY

## TOOLKIT:

For improved pediatric HIV diagnosis, care and treatment in high HIV prevalence countries and regions

## OVERVIEW OF THE PEDIATRIC HIV TREATMENT ADVOCACY TOOLKIT

► Welcome to the Pediatric HIV Treatment Advocacy Toolkit! The toolkit was developed by members of the Interagency Task Team (IATT) pediatric working group to support efforts in advocating for increased commitment to, and resources for, pediatric HIV diagnosis, care and treatment in high HIV prevalence countries and regions.

### WHY FOCUS ON PEDIATRIC HIV?

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- Children living with HIV are some of the most vulnerable members of society. Each day that goes by, almost 800 HIV-positive children die because of lack of access to treatment and care. Ensuring their well-being and protecting their human rights is our shared responsibility
- Although many countries have made great strides in prevention of mother-to-child HIV transmission (PMTCT), less progress has been made in scaling-up pediatric HIV diagnosis, care, support and treatment.
- Recent estimates from UNAIDS are that a staggering 2.3 million children younger than 15 years of age are living with HIV, about 90% of whom reside in Africa.
- 1.3 million children need HIV treatment now, but only 28% in need are receiving it, compared with 37% of adults. In many countries in Africa, the disparity between pediatric and adult access to treatment is much greater.
- HIV-infected infants have an exceptionally high mortality – approximately 30% will die by their first birthday without access to HIV care and treatment. Unfortunately, access to treatment among infants is even lower than among older children.
- Adolescents living with HIV are a growing group in need of services.
- Bottlenecks limiting pediatric treatment include poor access to diagnosis, weak systems for patient retention, few health centers and providers equipped to deliver pediatric ART, and drug regimens that are more complex to administer than adult regimens.
- Mortality from pediatric HIV contributes significantly to overall child mortality especially in high-burden countries. In order to achieve MDGs 4 & 6 by 2015, we must take action now.

### WHY NOW?

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- “Treatment 2.0” is a global initiative to re-galvanize efforts to achieve universal access for adults and children living with HIV through radically simplified HIV treatment with optimized drug regimens, point-of-care diagnostics, and decentralized service delivery.
- The *Global Plan towards the Elimination of New HIV infections among Children by 2015 and Keeping their Mothers Alive* is a new effort to reduce new HIV infections in children by 90% over the next 4 years through improved access to PMTCT, maternal treatment and infant testing.
- Both of these global programs provide an unprecedented opportunity to address the burden of pediatric HIV. Elimination of MTCT will result in far fewer infected children and as more HIV-exposed infants are tested, a greater proportion of those that are infected will be identified.
- As treatment becomes simpler and more decentralized, it will become easier to provide access to treatment for children living with HIV in urban and rural areas.

- Treatment for infants and children is an essential element of both Treatment 2.0 and Elimination of MTCT. Even as the most effective PMTCT interventions are widely scaled-up, there will be a continuing need for pediatric treatment, both for the 2.3 million children already infected and for those children who become infected despite PMTCT.

## **WHAT IS THE PURPOSE OF THE ADVOCACY TOOLKIT?**

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The use of this toolkit is aimed at generating a commitment among Ministries of Health (MOH) and relevant policymakers and partners to prioritize pediatric HIV treatment and for these policymakers to take measurable actions to increase access to and quality of pediatric HIV treatment coverage.

## **HOW CAN ADVOCACY INCREASE SUPPORT FOR PEDIATRIC-FOCUSED HIV PROGRAMMING?**

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In countries with strong commitment from national level leaders who have assigned the necessary financial resources to pediatric HIV programs, progress has been made in scaling up pediatric HIV diagnosis, care and treatment. Advocacy helps policymakers and decision makers understand the positive impact that these programs have on their constituents. Advocacy also helps galvanize the political support needed for policymakers to take a stand and make children a priority in their respective countries.

## **HOW CAN THE TOOLKIT BE USED?**

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The toolkit equips advocates with clear and concise messages that are primarily targeted at MOH. Donors and other partners are also important target audiences. There are five different components included in this toolkit that can be used separately or in combination with other components of the toolkit. Brief descriptions of the different components are listed below.

1. *Talking Points*: Talking points can be used for short presentations or briefings with MOH, donors, and other key stakeholders.
2. *Slide Deck*: The PowerPoint slide deck can be used for more extended briefings with these audiences. The slide deck may be used as a whole, or in excerpted form, depending on the audience, length of time available for briefing, and focus of discussion.
3. *Two Pagers*: Two pagers can be left with MOH officials, donors, and other key stakeholders so they have information that they can keep with them and refer to on the following topics:
  - Expanding Access to Early Infant Diagnosis of HIV
  - Task Shifting of Pediatric Antiretroviral Therapy
  - Rationalizing Pediatric ARV Formularies: Access to Optimal Formulations
  - Adolescents Living with HIV: Special Needs to Meet
  - Increasing Retention in Pediatric HIV Programs
  - Setting Higher National Targets for Pediatric HIV Testing and Treatment
4. *Video*: Sam Kauffman's film "Kids Living with Slim" can be shown to MOH and donors to highlight personal stories and the everyday realities of children living with HIV.
5. *List of resources*: This list of resources includes all references for the two pagers and can be shared with MOH or donors who are interested in more detailed information or supporting evidence about these issues.

## **WHO DO I CONTACT IF I HAVE QUESTIONS?**

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If you have any questions about the toolkit please contact *Shaffiq Essajee* at [essajees@who.int](mailto:essajees@who.int)

## SETTING HIGHER NATIONAL TARGETS FOR PEDIATRIC HIV TESTING AND TREATMENT

► *Setting better country-level targets for pediatric HIV testing and treatment is fundamental to eliminating pediatric AIDS, assuring equitable access to ART for children, and achieving the Millennium Development Goals. Urgent action is essential to reverse the neglect of children in the ART scale-up.*

### THE ISSUE

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Globally, children living with HIV have significantly worse access to treatment than adults. In 2009 estimated coverage for children in need of antiretroviral therapy (ART) was 28 percent, compared with 37 percent for adults. In many high-burden countries in Africa, the gap is much greater. Several countries estimate that pediatric coverage is less than half that of adults.

As a first step in ending this relative neglect of children living with HIV, countries need to set ambitious yet attainable targets for pediatric ART at all levels—national, district, and facility. Such targets can help planning processes better address pediatric ART. They also should facilitate accountability for results by giving programs specific numbers to measure their progress against.

Many countries currently have pediatric ART targets, but gaps are common:

- Targets are set at a national level only and have not been translated into local numerical targets that districts and sites could find useful for planning and monitoring.
- Targets are often not specifically set for children under two years old, who are the most vulnerable to mortality and typically have the least access to treatment.
- Targets for pediatric testing, which are the gateway to treatment, are often lacking.

**Targets should include an overall goal of at least 80 percent of children in need receiving ART.**

### THE EVIDENCE

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Some of the most dramatic evidence that targets can catalyze increased access to HIV treatment comes from WHO's "3 by 5" Initiative, which set a global goal of having 3 million people enrolled in HIV treatment in low- and-middle income countries by 2005. Based on this global goal, countries set specific numeric targets for ART at the national and sub-national levels. Countries used these numeric targets to inform their planning processes, monitor progress, and mobilize resources. Although the goal of "3 by 5" was not reached, it is widely recognized that the targets accelerated the global ART scale-up, which by 2010 had reached more than 5 million people.

Unfortunately, within the broader treatment roll-out, pediatric targets have been largely neglected in favor of overall ART targets. Furthermore, the 2010 WHO guidelines have expanded the eligibility criteria for children, including recommending ART initiation for all children age two and younger, but many countries have yet to increase their existing pediatric targets to reflect these new recommendations.

### LESSONS LEARNED

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Experience from "3 by 5" (and other public health programs) has demonstrated this:

- **Time-bound targets help ensure a sense of urgency** and drive among program managers.

- **Setting district-level targets assigns expectations and accountability locally**—an important function.
  - **Clear targets make implementation more effective** by, for example, improving targeting of training and ensuring that appropriate quantities of supplies reach sites.
  - **Targets should be ambitious yet attainable**
  - **Setting targets can help to mobilize and target resources**, including financial, human, and political commitments.
2. **Sub-national numerical targets based upon the national goal**
    - Numerical targets need to be set at national, district, and facility levels.
  3. **The specific subset of children under age two receiving ART**
    - Addressing pediatric AIDS requires reaching these children.
  4. **The eligibility criteria for treatment under WHO 2010 guidelines**
    - Under these guidelines many more children are eligible for treatment, including all infants infected with HIV.

## RECOMMENDATIONS

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To ensure that policy-makers, public health managers, and health care providers at every level are aware of the urgency of scaling up pediatric HIV-related treatment, **countries should develop and utilize improved national pediatric treatment targets.**

Targets should reflect and include the following:

1. **An ambitious, but achievable national goal**
  - Children with HIV should have at least equal access to ART as adults.
  - A goal of at least 80 percent coverage is a good starting point for deliberation in-country
  - Planning and resources may need adjusting to assure equitable access for children

5. **Pediatric HIV testing, which is necessary before treatment**
  - Setting targets for the number of children receiving virologic testing within the first two months of life is important to reach the most vulnerable children.

Additionally, target-setting for pediatric HIV testing and treatment should be closely coordinated with the setting of other HIV-related targets, especially for prevention of mother-to-child transmission (PMTCT) and adult ART. As countries adjust targets to reflect the goal of eliminating mother-to-child transmission of HIV, improved pediatric testing and treatment targets should also be developed.

## EXPANDING ACCESS TO EARLY INFANT DIAGNOSIS OF HIV

► *Early infant diagnosis (EID) and treatment of HIV could save many young lives. The testing process is complex, however. As a result, few infants are tested, and just a fraction of those who test positive start treatment. Still, several countries have proved that with focus and commitment, coverage of EID and early treatment can increase greatly.*

### THE ISSUE

Without treatment, 30 percent of HIV-positive children die before their first birthday. With antiretroviral therapy (ART) started at six weeks of age, approximately 95 percent can survive the first year of life. The process of diagnosis and treatment initiation, however, is complex, involving multiple steps and participants. Because this process often breaks down, many infants are dying.

Early diagnosis of infants is the crucial first step to identification on infection and provision of life-saving treatment. For adults, rapid HIV antibody diagnosis provides results in minutes, but early infant diagnosis (EID) requires a different approach using virologic testing which is both technically more complex to perform and practically more difficult to deliver as a service. HIV-exposed infants should be tested at six weeks or as soon as possible thereafter. Infant blood samples are sent as dried blood spots to a laboratory that has the required equipment. This laboratory may be close by but could also be far from the site. The results then need to be sent back to sites and returned to care-givers in a timely manner. Finally, infants who have tested positive must initiate ART.

This chain of events requires many elements within the health system to coordinate their activities. EID must be supported by ongoing investments in capacity building, logistics, and infrastructure. Due in large part to this

complexity, the availability of EID is very limited. Only an estimated 15 percent of HIV-exposed infants worldwide benefit from EID.

However, several low-income countries have demonstrated that with focus and commitment, coverage can greatly increase.

### THE EVIDENCE

Uganda, Senegal, Namibia, and Cambodia conducted a step-by-step review of their EID services chain. They found that the number of EID tests increased dramatically over the course of the study, from 2007 to mid-2009. Still, in 2008 only five percent of HIV-exposed infants received tests in the first two months of life (Namibia was the exception – there, an estimated 50 percent of infants received a test in the first two months, and overall 86 percent of all HIV-exposed babies were tested with EID). Low rates of testing were attributed to both poor coverage and low uptake at sites that did offer EID. High staff turnover and poor supervision meant that many sites could not submit samples, even though they had supplies and had received training.

Among the infants tested, up to 44 percent never received results. In Senegal, Uganda, and Cambodia, only 22 to 38 percent of infants that tested positive initiated ART. Long delays in returning results from labs to sites, averaging over 30 days in two countries, help to account for high loss to follow-up.

Spurred by the findings, these countries began addressing gaps in their programs. At sites that implemented Uganda's EID Strengthening Program (see box), the percentage of HIV-positive children who received test results increased from 66 to 78 percent. Among these, the percentage enrolling in ART rose from 57 to 97 percent.

### LESSONS LEARNED

- It is feasible for a low-income, largely rural country to achieve high EID coverage, as Namibia has shown.
- Reviews of EID services data can improve performance. Reviews should include not just statistics on testing but also how many infants that test positive are enrolled in ART.
- To increase EID coverage, different entry points for HIV-exposed infants need to make active referrals (i.e., MCH services, HIV care and treatment services, hospital wards, nutrition programs, immunization programs, etc.). This requires strengthening counseling on EID during all relevant PMTCT and MNCH contacts.
- To reduce loss to follow-up, standard operating procedures are crucial, linking sample collection and result return with counseling, clinical care, and follow-up. All staff need to know the EID sample flow, patient flow, and who has responsibility for HIV-exposed infants, including ART enrollment.
- To reduce turn-around time, strong management and two-way communication are important to ensure that the available labs are being used to their maximum capacity. Collection sites, labs, couriers, and partners all must work together.

### Uganda's EID Strengthening Program:

1. Set up an EID Care Point within MCH or ART to manage all care of HIV-exposed infants
2. Integrated routine care into the EID process and established regular visit schedules
3. Improved tracking tools to follow infants
4. Established/strengthened referral systems between EID Care Points and labs
5. Improved coordination and communication between EID Care Points and ART clinics
6. Strengthened and standardized counseling of care-givers.

- Innovative ways to return results can help—faxing, e-mail, SMS messaging, and printing results at hub laboratories.

### RECOMMENDATIONS

- Increase commitment to scaling up EID. Despite the challenges, most infants in need can be reached.
- Regularly review data to improve performance. Governments should play a more active role in ensuring that the site staff running the day-to-day services routinely collect patient data and report regularly, including infant outcomes.
- Strengthen management, coordination, and communication between labs and sites. In Namibia and Kenya, strong management assures short lab turn-around times, even though they have few labs.
- Invest in improving infant care and post-test outcomes. Better counseling, standard operating procedures, and clear assignment of responsibility for HIV-exposed infants are crucial.
- Focus not just on EID but also on early infant treatment. All infants who test positive must be started on ART rapidly. This is the ultimate goal of EID.

## INCREASING RETENTION IN PEDIATRIC HIV PROGRAMS

► The extent and significance of loss to follow-up among children in HIV programs in resource-poor settings is only now becoming clear, and it is estimated that over half of HIV positive children will be lost along the continuum of care. Programmatic interventions should be designed to overcome the specific causes of attrition in pediatric patients at policy, facility and community levels.

### THE ISSUE

Improving patient retention is emerging as crucial to the impact of HIV/AIDS treatment and care programs. Among those most likely to drop out of care programs are HIV-exposed and infected children. Over 50 percent of HIV-positive children are lost at various points along the continuum of care (see graph below).

Significant effort has focused on starting new patients on antiretroviral treatment. In contrast, attention to their long-term retention in care and treatment has been limited.

Attrition occurs at all points along the care continuum, and in children this stretches from the antenatal period through infancy, childhood, adolescence and, ultimately, through the transition to adult HIV care. With ongoing care and treatment across these stages, the vast majority of HIV-positive children can survive into adulthood.

There are several reasons why many HIV-positive children are not enrolled in care and treatment services. Examples include failure to identify

infants at risk for HIV infection, poor follow up of known HIV-exposed infants, weak referral linkages between testing and treatment services, limited knowledge and experience with pediatric diagnosis and treatment, and too few pediatric HIV care sites.

After enrollment, the retention of children in care and treatment is arguably more complex than it is for adults. Compared to adults, children have additional vulnerabilities, including more rapid disease progression, childhood-specific medical issues, dependence on caregivers, and transition to independence during school years and adolescence.

### THE EVIDENCE

The first and largest gap falls between the infants who are exposed to HIV and those who receive an HIV test. In 2009, an estimated 1.4 million HIV-exposed infants were born but only 88,200 (6%) received EID services. Due to poor tracking and services to HIV-exposed infants and their HIV-positive mothers, an estimated 370,000 new pediatric infections occurred in 2009. Even among infants who test positive, typically over one-third never enroll at an ART site. Without treatment, the median survival of HIV-positive infants is only two years.



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