



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?

- 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?

- “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?

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?

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?

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?

If you have any questions about the toolkit please contact *Shaffiq Essajee* at 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

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

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

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

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.

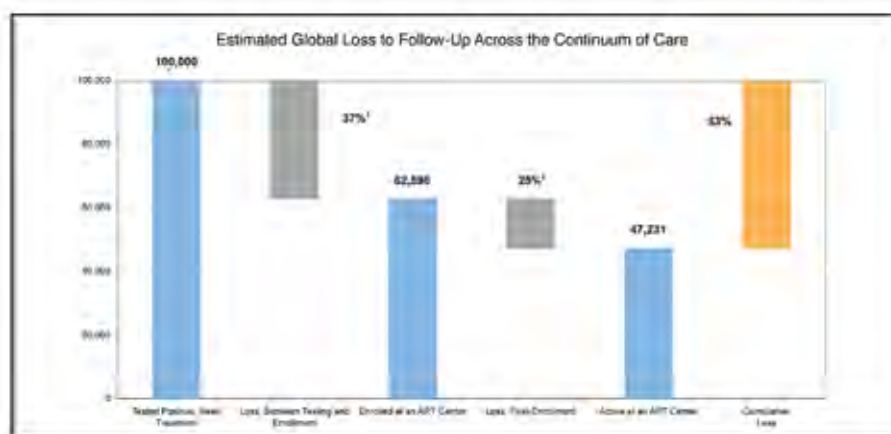
THE EVIDENCE

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.

Once they enroll at an ART site, attrition is usually greater for children on pre-ART than for those on ART. For example, a 2009 UNICEF early infant diagnosis survey in Cambodia, Senegal, and Uganda found that 50–58 percent of positive infants enrolled in

pre-ART care and eligible for treatment were never initiated on ART.

Among those who do start ART, 10 to 20 percent are lost to follow-up after initiation—the majority



¹ Testing here refers to Early Infant Diagnosis testing only, based on a 5-country analysis of all patients from sites available to CHAI (n=4970) in Cameroon, Ethiopia, Kenya, Swaziland, and Zambia.

² Based on 8-country analysis of all patient charts from sites at which data were made available to CHAI (n=18,077) in Cameroon, Dominican Republic, Ethiopia, Kenya, Nigeria, Rwanda, Swaziland, and Zambia.

during the first year of treatment. While most data collected on retention focuses on this group, it accounts for a relatively small percentage of the estimated total pediatric attrition.

With treatment, an increasing number of HIV-infected children are surviving into adolescence and adulthood. Data on this group are limited, but such issues as increasing self-responsibility and pressures from school or peers may contribute to poor adherence to treatment or high drop-out rates.

LESSONS LEARNED

Across programs, common observations include the following:

- **Good quality testing and treatment services are crucial to retention**—in particular, appropriate and timely access to clinical

services, high-quality post-test and pediatric-focused counseling, addressing human resource shortages, and maintaining supply chains.

- **Weak data management systems**, including referral systems, make it difficult for health care workers at testing and ART sites to trace a patient's medical history or to identify when a patient is lost until long after she or he has missed an appointment.
- **Children on pre-ART get less attention** than those on ART, leading to higher loss rates.
- **Direct costs of care**, such as HIV tests, ARVs, treatment for opportunistic infections, and user fees at HIV clinics, discourage patients and their families from staying in care. So do such indirect costs as transportation to the health facility and loss of income on clinic visit days.

RECOMMENDATIONS

As highlighted below, solutions should be tailored to the problems at specific loss points.

Attrition Between Testing and ART Site

Problems:

- Caregivers not receiving test results due to slow turnaround and poor data management
- Caregivers lack understanding, urgency around importance of early testing
- Caregivers do not return to collect test results
- Lack of referral mechanisms between PMTCT, EID and pediatric care and treatment services

Solutions:

- Decentralization of EID and ART services
- SMS printers to expedite return of test results
- Improved documentation to track turnaround time and when caregivers receive results
- Triplicate referral forms, and care conferences to identify referrals that are not completed
- Community tracking of exposed infants and follow-up of those who do not present for EID at six weeks
- Peer mother programs to provide additional support to families

Attrition from ART Site

Problems:

- Pre-ART patients not followed regularly
- Lack of appointment tracking, patient data
- No outreach mechanism to find lost patients
- Lack of access to EID services
- Poor quality of care due to HCW shortages

Solutions:

- Elimination of user fees
- Improved patient tracking systems (electronic or paper-based) for timely identification of patients with missed appointments
- Collecting patient contact information at each visit
- Expanded access to EID services
- Task-shifting to strengthen counseling, case management, and tracking services
- Provision of adolescent-focused services
- Support groups for families and adolescents

RATIONALIZING PEDIATRIC ARV FORMULARIES: ENSURING ACCESS TO OPTIMAL DRUGS

► *In recent years, new formulations have been introduced that provide adherence advantages for children. It is critical to ensure that all children in need of treatment have consistent access to these high-quality ARVs. However, a large number of duplicative formulations exist that fragment the pediatric marketplace creating low demand for individual products and place the supply at risk. Rationalizing pediatric ARV formularies will enhance HIV treatment for children by limiting the risk of stockouts and ensuring all children are able to benefit from these new formulations.*

THE ISSUE

Pediatric HIV treatment in resource-limited settings has improved dramatically over the past five years. Worldwide, the number of children on antiretroviral treatment (ART) has grown from 75,000 in 2006 to over 365,000 in 2009 coupled with the introduction of innovative pediatric ARV formulations.

Since 2006, UNITAID-CHAI (Clinton Health Access Initiative) project has purchased pediatric ARVs by consolidating orders from 34 countries. The goal of this innovative system of pooled procurement was to increase incentives for manufacturers and lower prices for national programs. The project was a time-limited intervention designed to transition to new funding sources once these goals had been achieved.¹

This procurement system, coupled with scale-up, has transformed the pediatric marketplace by incentivizing generic manufacturers to create newer and better pediatric formulations. As a result, the range of pediatric-specific antiretroviral (ARV) formulations available has also grown. Currently, over 30 pediatric ARV formulations have been WHO pre-qualified, or approved or tentatively approved by the US Food and

Drug Administration, including eight unique pediatric-strength fixed-dose combinations (FDCs) and eight dispersible formulations. FDCs and dispersible products significantly improve adherence and simplify care. They also streamline procurement and supply management by reducing the number of products that have to be purchased, stored, and distributed.

THE EVIDENCE

Despite initial success in scaling up of affordable treatment for children, the pediatric ARV marketplace is still particularly vulnerable to supply disruptions. Firstly, children comprise a small part of the population—in 2009, only seven percent of all ART patients. Secondly, children require different formulations according to their weight and/or age. Thus, children need a greater number of products than the adult population. Moreover, some programs and practitioners continue to use outdated formulations, further fragmenting demand across multiple products for equivalent regimens.

On the supply side, product batch sizes dictate the minimum quantity that manufacturers produce at one time. As the number of formulations increase, order sizes may decrease below the minimum batch sizes. As a result, lead times on orders will

¹ The UNITAID-CHAI pediatric project began transitioning to new funders on a rolling basis in 2010 and is slated to completely phase out by the end of 2012.

lengthen and become more variable, increasing the risk of stockouts.

These market conditions underscore the need to rationalize pediatric formularies to include only optimal products. By phasing out syrups and single-drug products in favor of more affordable, easier to use dispersible and FDC formulations, overall order volumes may increase for the optimal formulations. Reduction in the number of products procured will also streamline forecasting, supply chain and distribution systems.

LESSONS LEARNED

Rationalizing pediatric ARV procurement is essential to ensure the sustainability of the market and national pediatric treatment programs and to improve care for pediatric patients. As new and better products have become available, deciding which new products to adopt and roll out, while phasing out old formulations, can be daunting. National guideline committees tend to focus on ART options rather than formulation selection, and countries may not have well-established processes to routinely review ARV product lists that guide procurement decisions. Additionally, programs with multiple implementing partners may use a wide variety of formulations between them.

Clinicians' preferences for certain products or discomfort with completely eliminating some formulations can make it difficult to phase out older products. Hands-on educational activities can make health care staff more

Encourage governments to rationalize their pediatric products by identifying syrups and single-drug products that can be fully phased out in favor of cheaper, easier to use dispersible and FDC formulations.

By pooling procurements and ordering quarterly, the UNITAID-CHAI project has increased access to many low-volume products that individual countries would not have had sufficient demand to order. In 2010, UNITAID-CHAI's 34 beneficiary countries covered 67 percent of pediatric patients on ART and 97–100 percent of global pediatric FDC use (Waning 2010).

aware of difficulties with particular products and thus encourage adoption of formulations that simplify administration, such as FDCs. For most programs, 10 to 12 ARV formulations can meet the needs of all pediatric patients.²

RECOMMENDATIONS

To secure the uninterrupted supply of pediatric ARVs, national HIV programs and their partners should consider these actions:

Rationalize pediatric ARV formularies

- Conduct a pediatric formulary audit or rationalization workshop to reduce the number of procured formulations, removing syrups and single drugs in favor of FDC and dispersible formulations.
- Set up a working group or task force to evaluate pediatric formularies regularly to ensure consolidation around a sub-set of preferred formulations.

Accelerate the phase-out of old formulations

- Identify strategies and secure resources for switching patients to optimized treatment products.
- Monitor the transition and coordinate efforts to actively manage the phase-out of older products.

Participate in pooled procurement/ coordinated buying mechanisms

- Evaluate options available for each country context to facilitate access to lower volume pediatric products.

² The WHO is leading the IATT pediatric sub-group to develop a list of preferred pediatric formulations to support in country reviews.

TASK SHIFTING OF PEDIATRIC ANTIRETROVIRAL THERAPY

► Where policies require physicians to initiate and manage antiretroviral therapy (ART), shortages of physicians severely limit children’s access to this life-saving HIV treatment. Training other health care personnel, such as nurses, to take on certain tasks can be the answer. This task shifting has shown the potential to offer high-quality, cost-effective care to more patients, especially at rural sites, with the added benefits of increasing utilization and reducing loss to follow-up.

THE ISSUE

Nearly seven of every ten children who need ART do not currently receive it. One reason: In developing countries the shortage of physicians with pediatric experience has limited expansion of pediatric HIV care and treatment.

Sub-Saharan Africa has two-thirds of the world’s HIV cases but only three percent of the world’s healthcare workforce. In parts of southern Africa, there is only one doctor per 100,000 people and as few as one pediatrician per 500,000. Furthermore, doctors tend to work in large urban HIV facilities, which rural people find hard to reach.

Task shifting (also known as task sharing) means the delegation of tasks historically performed by highly qualified personnel to personnel with fewer qualifications who receive intensive training focused on specific tasks and skills. For example, physicians can shift certain tasks to nurses and other non-physician clinicians (NPCs) (see Table 1 below).

Many developing countries cannot adequately scale up HIV care and treatment without broadening the roles of health care providers. Recognizing this, WHO, UNAIDS, and PEPFAR have formalized joint guidelines on implementing task shifting to address personnel shortages and offer expanded, high-quality services.

Nurses in particular can play a much greater role in ART initiation and monitoring. Nurses are more numerous and more available than doctors, especially at rural sites where many children could receive ART and other care. Indeed, many rural clinics are staffed entirely by non-physician health care workers, many of them nurses. Still, policies guiding roll-out of ART often restrict delivery of crucial services to physicians, even where there are few or none.

THE EVIDENCE

Task shifting has been shown to expand rollout where numbers of providers are limited, and such evidence is growing. A recent meta-analysis analyzing the strengths and weaknesses of task shifting found 84 high-quality studies (51 with outcomes), including research in 10 sub-Saharan countries, and several including pediatric populations (See Table 2). The most common type of task shifting was delegation of ART initiation and monitoring from doctors to other clinicians, mainly nurses.

Table 1 Types of task shifting commonly seen in Africa¹³.

Type of task shifting	Definition	Example
Type I	The extension of the scope of practice of <i>non-physician clinicians</i> in order to enable them to assume some tasks previously undertaken by more senior cadres, e.g. doctors	Clinical officers deciding eligibility and prescribing ART (Malawi)
Type II	The extension of the scope of practice of <i>nurses</i> and <i>midwives</i> in order to enable them to assume some tasks previously undertaken by senior cadres	Nurses treating opportunistic infections and prescribing ART (Botswana, Ethiopia, Uganda, Malawi)
Type III	The extension of the scope of practice of <i>community health workers</i> or <i>lay providers</i> in order to enable them to assume some tasks previously undertaken by more senior cadres, e.g. nurses and midwives, non-physician clinicians or doctors	Community health workers providing ART counseling and HIV testing (Uganda, Rwanda, Malawi)
Type IV	<i>People living with HIV/AIDS</i> , trained in self-management to assume some tasks related to their own care that would previously have been undertaken by health workers	Provision of basic HIV support, treatment adherence and psychosocial support (Botswana, Kenya, Nigeria, South Africa)
Type V	The extension of the scope of practice of other cadres that do not traditionally have a clinical function, e.g. <i>pharmacists</i> , <i>laboratory technicians</i> , <i>administrators</i> , <i>record clerks</i>	Record clerks filling in basic patient information and measuring body weight at HIV clinics (Malawi)

ART: antiretroviral treatment.

Key findings were these:

- Nine studies showed that task-shifting achieved equal or better quality of care than care that physicians provided.
- Four studies documented reductions in patients' waiting times and loss to follow-up.
- Five studies found increased access to highly active antiretroviral therapy (HAART) through expanded clinical capacity.
- Four studies concluded that task shifting is cost-effective.
- Most but not all studies found good agreement between physicians and non-physicians on management decisions.

While most studies have focused on task shifting for adult HIV services, many of the same issues apply for children. However, given the special issues of diagnosis, care, and treatment of infants and children, special attention must be given to training and equipping staff to manage pediatric patients and their needs.

RECOMMENDATIONS

Given the documented successes of nurses and other non-physician clinicians, task shifting should be promoted as an effective strategy to address shortages of human resources for HIV treatment and care. Task shifting should be considered especially where provider shortages

threaten ART rollout. Concrete steps towards effective task-shifting include: (1) adjusting policies to promote appropriate task sharing; (2) developing a framework for the roles of different providers; and (3) creating mechanisms to supervise and support nurses and others taking on new roles. Challenges will need to be faced: providing adequate and sustainable training, support, and pay for staff in new roles; integrating new members into health care teams; and complying with regulation, especially where policies discourage needed sharing of key tasks.

Table 2. Lessons Learned: Country Examples

Country	Examples of Successful Task Shifting	Reference
Lesotho	Nurses treated both children and adults, leading to increased enrollment of patients, increased retention of children in care, and decreased numbers of adults with very low CD4 counts (<50)	Cohen, Lynch et al. 2009
Mozambique	Non-physician care givers achieved higher levels of adherence to ARVs in the first 6 months after initiating ART and were less likely to be LTFU than those seen by physicians	Shen, Misesk et al. 2010
Nigeria	Nurse ART treatment helped reduce waiting time by 4 hours	Udegboka et al. 2009
South Africa	Compared outcomes between nurse and doctor led management of adults (neither group had previous HIV experience) and found no difference in mortality, viral failure, or immune recovery	Sanne, Orrell et al. 2010
Uganda	Both nurses and clinical officers demonstrated strong agreement with physicians in assigning clinical staging and deciding whether to initiate antiretroviral therapy.	Vasan, Kenya-Mugisha et al. 2009
Zambia	Good pediatric outcomes reported in clinics managed by clinical officers and nurses.	Bolton-Moore, Mubiana-Mbewe et al. 2007

ADOLESCENTS LIVING WITH HIV: SPECIAL NEEDS TO MEET

► Adolescents living with HIV (ALHIV) have unique and pressing needs. Programs tailored to meet those needs form a crucial part of the effort to eliminate pediatric HIV worldwide. Comprehensive, non-discriminatory, and confidential sexual and reproductive health information and services should be made available for these young people. Transitional support for adolescents reaching adulthood is also vital.

THE ISSUE

Generations of babies born with HIV are now surviving into adolescence and young adulthood, thanks to global improvements in early infant diagnosis (EID), care, and treatment of HIV, coupled with increased access to highly active anti-retroviral therapy (HAART) in the neonatal period. Whether infected at birth or later in life, adolescents living with HIV face psychosocial, treatment, care, and reproductive health challenges that the health sector is only now beginning to recognize.

Adolescence is a time of change, exploration, and self-discovery. It is a vulnerable time, particularly for adolescents living with HIV, who are more likely than other age groups to fail to take their medications, to drop out of health care, and to engage in high-risk behavior.

Whether infected at birth or later in life, adolescents living with HIV face a variety of unique challenges that the health sector is only now beginning to recognize

Adolescents living with HIV are often the primary caregivers in their homes for siblings or others who also are living with HIV. Thus, their own treatment, care, and support are important to the care of others. Furthermore, late disclosure, self-denial or their family's denial, and limited access to information and services leads many to live with an

infection that they do not understand and do not know how to care for. Given these circumstances, health care services must reach out to these young people and learn how best to meet their needs.

THE EVIDENCE

Adolescents living with HIV often face mental health challenges due to HIV-related stigma and discrimination as well as to the direct effects of HIV infection on neurological functioning. These challenges can lead to non-adherence to HAART, disengagement from care, lower quality of life, and, ultimately, disproportionate rates of HIV-related morbidity and mortality.

Most service providers, particularly in rural settings, are not specifically trained to work with adolescents. Often, adolescents living with HIV feel unwelcome and discriminated against in clinical care settings. Additionally, hospitals and clinics struggle to transition their adolescents from pediatric to adult HIV care. Many countries develop policies for the provision of health services for young people but do not implement them. Meanwhile, service agencies continue to work in silos, competing for limited resources and duplicating efforts rather than collaborating and sharing best practices.

In many countries, sexual and reproductive health is seldom discussed with young people, or such discussions begin too late. Service providers often forget that adolescents living with HIV share the same needs for information as other adolescents. These young people may be sexually active, and they may want to have children. The reality is that many adolescents living with HIV are practicing unsafe sex, even though they know the risks.

When they have their own children, the stigma attached to teen and pre-marital pregnancy may push adolescents away from care and treatment for themselves and EID for their children.

LESSONS LEARNED

- **Mental health support** is crucial. A “one-stop shop” with medical *and* mental health services is needed, or else a strong network of providers with referral pathways.
- **Sexual and reproductive health services** should be comprehensive, non-discriminatory, and tailored to the specific needs of adolescents.
- **Transitional support** is vital. Close attention should be paid to the development of protocols and specialized clinics for transitioning adolescents from pediatric to adult care.
- **Meaningful involvement of adolescents living with HIV** is essential to the design, delivery, and evaluation of treatment, care, and support services.

RECOMMENDATIONS

1. **Establish mechanisms to actively identify undiagnosed adolescents** through schools, facility-based provider-initiated testing and counseling, outreach and community-based HIV testing and counseling, and prevention of mother-to-child transmission services.
2. **Adopt a comprehensive, multidisciplinary approach to services** that includes mental health in treatment and care.

3. **Provide sexual and reproductive health information and services** for adolescents living with HIV that are comprehensive, confidential, and non-discriminatory. Such services should start from the age of puberty and be available in healthcare settings, schools, and communities.
4. **Conduct a participatory review of current HIV services** in the country to assess how well they address the needs of adolescents living with HIV.
5. **Review and adjust national plans** to ensure that they address adolescents living with HIV, and develop a mechanism for regular monitoring and review to ensure that gaps are being filled.
6. **Develop, implement and evaluate guidelines and provider trainings focused on transition of care and sexual and reproductive health.** Ensure that these policies and services are streamlined and monitored for efficacy once implemented and that ALHIV are meaningfully involved at all stages.
7. **Conduct periodic evaluations, behavioral and sero-surveys, and needs assessments** to identify program bottlenecks, quantify needs, and determine the resources required to provide services at full scale.
8. **Encourage collaboration** and knowledge-sharing between organizations in order to improve efficacy of services.



One in three children with HIV dies before their first birthday without treatment. While HIV-exposed infants must be tested and diagnosed early in order to begin antiretroviral therapy (ART) within this critical time period, currently only 15% of exposed infants worldwide receive early HIV testing with appropriate virologic tests. By affirming their commitment to early infant diagnosis and establishing standards based on proven strategies for enrollment and retention of HIV-exposed infants in care, low-resourced settings can successfully link children with HIV to needed treatment.



Up to one in three children diagnosed with HIV infection do not receive life-saving therapy. One in four children enrolled in care are lost before starting ART, and one in five children on ART are lost to follow-up in the early years of therapy, most within 12 months of initiation. Once lost, median survival for a child with HIV is two years. To keep these children alive, it is essential to eliminate financial and other barriers to provision of ART and to ensure high-quality care that prevents children from falling through the cracks.



Low market volume and inconsistent ordering threaten to interrupt the supply of life-saving pediatric antiretroviral drugs (ARVs). To address this problem, the international community began pooling orders to build the market for pediatric ARVs. Since international financial support for pooling orders will end in 2012, governments and their partners must act quickly to avoid any disruption of supply and to ensure continued development of new pediatric formulations. By actively managing product formularies and focusing on new, more easily administered drugs, programs can minimize supply disruptions and increase patient adherence at the same time.



Children succumb to HIV much faster than adults, yet globally, children living with HIV have less access to treatment than adults. Barely one in four children in need of ART is receiving it. Setting targets focused on children can help end this neglect, and can ensure appropriate expectations, planning, and accountability. Targets will also restore the sense of urgency required so that at least 80% of children requiring life-saving ARVs receive them.



In parts of the world hardest hit by the HIV epidemic, there can be as few as one doctor per 100,000 patients. Where policies require doctors to initiate and manage ART, doctor shortages can severely limit children's access to life-saving HIV treatment. Training other health care personnel, such as nurses, to take on certain tasks is a proven solution to these staff shortages. Task shifting of ART has shown the potential to offer high-quality, cost-effective care to more clients, especially at rural sites, while also reducing loss to follow-up.



Generations of babies born with HIV are now surviving into adolescence, and this growing population has unique and pressing needs. In the context of late disclosure, denial, and limited access to information, adolescents living with HIV often find themselves coping with an infection that they do not understand or know how to care for. Meanwhile, service providers often lack training in how to support this age group. Comprehensive, non-discriminatory, and confidential sexual and reproductive health services for these young people should be made available at every possible point of care so that they can remain healthy during their transition into adulthood.

ADDITIONAL RESOURCES FOR PEDIATRIC HIV TREATMENT ADVOCACY TOOLKIT

EXPANDING ACCESS TO EARLY INFANT DIAGNOSIS OF HIV

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SETTING HIGHER NATIONAL TARGETS FOR PEDIATRIC HIV TESTING AND TREATMENT

World Health Organization and Joint United Nations Programme on HIV/AIDS (UNAIDS). 2006. *Progress on Global Access to Antiretroviral Therapy: A Report on "3 by 5" and Beyond*. Geneva: UNAIDS.

Why use this toolkit?

Globally, about **2.3 million children younger than 15 years of age have HIV.**

Their prospects for a healthy life are undermined when they are not tested for HIV at an early age, and provided with the treatment, care and support they need to thrive.

Produced by the Working Group on Pediatric Care & Treatment and the Interagency Task Team on Prevention and Treatment of HIV Infection in Pregnant Women, Mothers and their Children

This multi-media tool kit supports communication and advocacy with Ministries of Health and other key stakeholders. The tool kit lays out the evidence for an improved care, support and treatment response for children and young people, provides compelling reasons for scaling up that response, and recommendations on how to do it.

