Spotlight on ...
Pediatric HIV Care and Treatment
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In the last decade, the majority of global efforts to end AIDS in children have focused on prevention. Because 90% of pediatric infections are transmitted from HIV-positive mother to child during pregnancy, delivery, or breastfeeding, efforts have focused on prevention of mother-to-child transmission of HIV (PMTCT). The advancement of PMTCT resulted in an impressive 60% reduction of new infections among children by 2013, from a peak of 580,000 new pediatric HIV cases recorded in 2003. Despite these gains, there remain an estimated 2.9 to 3.5 million children and adolescents younger than 15 living with HIV in the world. All of these children could live an AIDS-free life through sustained antiretroviral therapy (ART). Sharing in the global commitment to ensure that every child is given the right to live a long and healthy life, the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) has maintained focus on ensuring that every child is not only protected from HIV but promptly diagnosed and initiated on lifelong treatment when infected.
Today, ART access among HIV-infected children and adolescent lags substantially behind access to PMTCT services among pregnant women. Pediatric ART initiation also lags behind adult HIV care and treatment enrollment: adult ART coverage reached 38% of HIV-positive patients, while pediatric ART covered only 24% of eligible children in 2013.1 In 16 high-burden countries in sub-Saharan Africa, fewer than 10% of children living with HIV received ART in 2013.2 Although scale-up of effective PMTCT and ART programs has resulted in significant reductions in AIDS-related deaths over the past decade among adults and children younger than 15 years of age, the number of deaths related to HIV among adolescents 10 to 19 years of age has increased by 50% between 2005 and 2012.3

In the absence of pediatric ART, more than 50% of HIV-infected infants progress to AIDS and die before their second birthday. Early initiation of ART has shown to dramatically improve health outcomes of HIV-infected children. By strengthening immunologic health, ART also leads to reductions in opportunistic infections and mortality, as well as improved long-term growth and neurological development. Informed by this evidence, in 2013, the World Health Organization (WHO) updated pediatric HIV treatment guidelines to recommend universal initiation of ART among HIV-infected children younger than five years of age regardless of viral load (the amount of virus replicating in the body), CD4 count (a diagnostic used to measure immunologic health), or clinical stage of HIV disease.3 These guidelines also called for relaxing the threshold of CD4 count to create wider access to ART among older children and adolescents (previous guidelines recommended ART to children with weaker immune activity as predicted by their CD4 measurements).
Global Challenges in The Pediatric HIV Treatment Cascade

The global commitment to improve pediatric HIV care and treatment has accelerated over the past few years. The need to expand treatment access to children is finding its way into national health plans and goals (an example of this can be found in EGPAF–Lesotho’s article, page 16), but at a much slower pace than implementation of the 2013 WHO recommendations for PMTCT and adult care and treatment programming. As of July 2014, only nine countries in Africa had aligned their national pediatric treatment guidelines with the WHO’s 2013 recommendation for immediate treatment initiation, regardless of viral load, CD4 count, or clinical stage, for HIV-positive children younger than age five.4

Prioritizing adaptation of global guidelines in countries is a first step toward reaching children in need. Adaptation of these guidelines will have to consider the entire pediatric HIV care and treatment cascade, from timely diagnosis of infection to sustained access and adherence to ART among children and adolescents. In order to implement these revised treatment guidelines successfully, countries and global partners need to understand the cascade—its benefits, shortfalls, and barriers.

Testing of HIV-Exposed Infants, Children, and Adolescents

Early testing of HIV-exposed infants is heavily reliant on retention of the mother-baby pair in the cascade of PMTCT services. The WHO’s current PMTCT recommendation calls for HIV testing among HIV-exposed infants at birth, 4–6 weeks and 9 months postnatal, and after breastfeeding cessation.6 Although technical and programmatic innovations to improve early infant diagnosis (EID) led to more than 1 million early infant tests performed in low- and middle-income countries in 2013,4 the vast majority of HIV-exposed infants did not complete the PMTCT HIV testing cascade.4 The percentage of children who are lost to follow-up in the PMTCT testing cascade by three months of age in 11 sub-Saharan African countries has been reported to be as high as one-third (34%).5 South African studies reported infant loss to follow-up rates at 12 months of age to be as high as 50–85%.5

Beyond the PMTCT testing framework, important health service entry points for children seeking medical, immunization, and nutritional care are not optimally used to identify HIV-exposed and HIV-infected children, and active provider-initiated case finding among infants, children, and adolescents remains quite limited. HIV-exposed children who are missed by EID are frequently never offered subsequent testing. HIV testing is not routinely offered to older children who access other high-yield diagnostic entry points (e.g., tuberculosis clinics, inpatient wards). Limited integration of pediatric HIV care with maternal, neonatal, and child health care (MNCH) also contributes to weaknesses in postnatal diagnostics and follow-up, as does low pediatric HIV service utilization.

As children grow into adolescence, those who have been perinatally infected and have been missed in the PMTCT cascade may have a very advanced disease and immune suppression requiring prompt initiation of ART. Those who have not been infected with HIV perinatally are entering a period of increased HIV risk as they become sexually active. All adolescents, independent of how they may acquire HIV, encounter a whole new series of HIV testing barriers such as need for parental presence and consent, and fear of disclosure of HIV status to peers and partners in stigma-saturated communities.

The low number of health care workers trained and skilled in pediatric HIV/AIDS care also limits access to HIV testing and subsequent linkage to care. Many health workers have limited knowledge of EID, and lack the skills and confidence to identify and manage infants, children, and adolescents living with HIV. Many health workers are reluctant to recommend HIV testing for children and adolescents and are inexperienced in counselling children and families.14
Linkage to Care and Initiation of Treatment

Early initiation of HIV-positive children on ART significantly improves their survival. However, substantial delays continue to occur in linking children diagnosed with HIV infection to treatment and care services. Among infants who do undergo blood sample collection for EID, eventual linkage to HIV care is often jeopardized by delays in the delivery of blood specimens to laboratories (if a laboratory is not on-site) for HIV polymerase chain reaction (PCR) testing, the return of those results to a facility (which can be quite slow in resource-limited locations with poor infrastructure), and the delivery of those final results to a caregiver. Five studies from sub-Saharan Africa reported high rates (31%–68%) of loss to follow-up of infants following blood sample collection for EID, often due to the long delays in accessing test results. Studies from sub-Saharan Africa suggest the lag from testing to ART initiation among infants and children can be anywhere from 16 to 23 weeks. Some published data have indicated that up to 50% of infants in Africa and Asia who tested HIV-positive never received their test results and were thus never connected to care and treatment.

Health care providers are also faced with limited choices of pediatric antiretroviral (ARV) drugs for children. The number of approved pediatric ARV drug formulations in the world remains limited due to multiple challenges, such as requirements for palatable and liquid formulations, need for multiple dose adjustments as the child grows, and unique safety issues. Due to the small size of the pediatric market compared to the adult market, the development of pediatric ARV formulations and diagnostic technologies for children is often considered by many manufacturers to be an ineffective use of costs. Moreover, procurement of pediatric ARVs represents another major obstacle to sustainability of ART in children in many resource-limited settings. Not surprisingly, program data suggest that stock-outs of ARVs occur significantly more frequently for pediatric formulations than for adult medicines.

Retention on ART and Virological Suppression

To ensure a long and healthy life, ART needs to be continued throughout a lifetime. For HIV-infected children and their caregivers, this means multiple transitions during treatment and care throughout different stages of their life and development. Loss to follow-up has been identified as a major obstacle in the success of pediatric ART. A pooled analysis of 16 pediatric HIV treatment programs in sub-Saharan Africa found substantial loss to follow-up of HIV-infected children. According to a study involving 17,000 children receiving ART in four African countries, 51% of children enrolled in HIV treatment before their first birthday were lost to follow-up within 24 months after initiation of ART.

Losses across the pediatric HIV treatment continuum greatly worsen health outcomes for children living with HIV. One study from Kenya, for example, estimates that only 14% of children living with HIV are virologically suppressed due to gaps in the continuum of care, especially the failure to identify infected children and initiate ART. Substantial loss to follow-up continues to occur after the start of treatment producing notably lower rates of viral suppression for children (60–70%) on ART compared to adults (90%).

Clinic characteristics factors, such as long wait times, understaffing, and loss of test results, as well as the lack of standardized patient information systems, can greatly contribute to the loss of children through the continuum of care. For older children and adolescents, loss to follow-up is frequently associated with the lack of age-appropriate counselling and psychosocial support, lack of adolescent-friendly care and facilities, adherence barriers to ART, nondisclosure of status within the family and community, and ineffective transition to adult care.
Turning the Tide on Pediatric HIV Care and Treatment

Global Commitment

The global community has prioritized pediatric and adolescent HIV and pledged major political commitment and funding in the last few years, to support scale-up of pediatric and adolescent HIV diagnostics, care, and treatment. The publication and subsequent implementation of the 2013 WHO treatment guidelines greatly facilitated prioritization of pediatric HIV care and treatment access by recommending ART for all HIV-positive children younger than five and expanding ART eligibility for older children (with CD4 counts below 500). With pediatric HIV treatment rapidly gaining momentum, success in achieving an AIDS-free world for children and adolescents is highly dependent on the close collaboration of major international health service donors, HIV program implemen- ters, and country governments. To answer this need, committed partners are already starting to come together through initiatives from the Global Fund, the Joint United Nations Programme on HIV and AIDS (UNAIDS), the U.S. President’s Emergency Fund for AIDS Relief (PEPFAR), and the Children’s Investment Fund Foundation (CIFF).

Global Fund

The Global Fund, a leading financial institution directing innovation toward the fight against AIDS, malaria, and tuberculosis, has assumed leadership of the Paediatric ARV Procurement Working Group and Procurement Consortium. The consortium (of which EGPAd is a member) includes leading partners and undertakes multipartner demand forecasting, the results of which are shared with suppliers. This consortium coordinates ARV drug orders for more than 50 countries.

UNAIDS

To drive global and national action on pediatric HIV treatment, UNAIDS, with the endorsement of EGPAd, WHO, UNICEF, and other partners, launched new treatment targets specifically for children in 2014. These targets are designed not only to encourage increased initiation of pediatric ART but also to address challenges around adherence and retention that affect long-term health outcomes as children move from infancy to adulthood. The 90-90-90 targets (see Figure 1) were set by UNAIDS in 2014 to ultimately help the world close the chapter on the HIV/AIDS epidemic by 2020. Through this initiative, UNAIDS committed to facilitate development of a road map for implementation of 90-90-90 targets. The commitment represents a major global shift to reach more children in need of HIV testing, diagnosis, care, and treatment.

PEPFAR and CIFF

In 2014, PEPFAR, in partnership with CIFF, launched the Accelerating Children’s HIV/AIDS Treatment (ACT) initiative. ACT is an ambitious initiative to double the total number of children receiving ART across nine priority African countries by the end of 2016: Cameroon, Democratic Republic of Congo, Kenya, Lesotho, Malawi, Mozambique, Tanzania, Zambia, and Zimbabwe. The long-term, overarching goal of ACT is to create an enabling environment for HIV/AIDS testing, care, and treatment services among infants, children, and adolescents, and a plan for continued expansion of pediatric ART services after 2016 using a sustainable approach.

In 2015, UNAIDS released revised targets: By 2030, 95% of children will know their HIV status, 95% of children diagnosed with HIV will receive ART, and 95% of children receiving ART will have undetectable viral loads.

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**FIGURE 1: UNAIDS 90-90-90 targets**

- **By 2020**
  - 90% of children living with HIV will know their status
  - 90% of children with diagnosed HIV infection will receive ART
  - 90% of children receiving ART will have undetectable viral load

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Innovative Approaches to Advancing Pediatric HIV Targets

Identifying and treating HIV early (within 12 weeks of birth) has been shown to reduce HIV-related mortality in children by 75%. To date, the feasibility of early ART administration among infants has been hampered by the delays in EID result turnaround time. Introduction of point-of-care technologies for EID in health facilities will allow for early identification and immediate return of results (results can be given to the caregivers the day that testing is performed). Other examples of innovative approaches to scaling up pediatric cascade targets include family-centered health systems approaches and an adolescent-friendly testing and care outreach.

Increasing Health System Capacity in Pediatric HIV

Much progress has been made in strengthening health systems in resource-limited settings and building skills among health workers to provide high-quality HIV care. However, the specific expertise and confidence to provide pediatric HIV services is lacking among many health workers in high-prevalence settings. To ensure effective provision of pediatric HIV diagnosis, care, treatment, and adherence counselling, health programs need to invest in staff and infrastructure. Investments such as development of national pediatric targets and national training plans to scale up revised guideline implementation, skill-building opportunities for health staff (see sidebar article on page 20), specific trainings of advanced practitioners to manage complicated cases or training of site managers to ensure management of HIV programs and supply chain, and consistent on-site mentorship and supportive supervision or task shifting can have a sustainable effect on pediatric HIV programs.
Engaging Communities to Support Identification of Children in Need and Linkage to HIV Care and Retention

Communities can play a critical role in expanding access to HIV care and treatment, particularly in the identification of HIV-exposed children and their linkage to care and retention in treatment. Community awareness and support have been associated with increased access to pediatric and adolescent HIV services. There are many opportunities to strengthen the role and capacity of the community to respond to the needs of HIV-exposed and HIV-infected pediatric populations:

- Involvement of community and traditional or tribal leaders in increasing community health education and HIV awareness has been associated with increased utilization of health services.
- Communication campaigns to foster demand for HIV testing (via radio, television, and print media) have proven successful in increasing access to HIV testing.
- Community health worker involvement has been associated with increased case finding, including enhanced referrals to integrated services.
- Psychosocial support systems, such as monthly child and adolescent peer support meetings (see page 12 for an example of such a program from EGPAF), have been associated with increased retention on ART.

Increasing the Number of Pediatric Formulations and Simplifying ART Regimens for Children

Progress has been made in streamlining and simplifying WHO guidance on recommended regimens and treatment approaches for children. In 2013, the Inter-Agency Task Team for Prevention and Treatment of HIV Infection in Pregnant Women, Mother and Children removed five complex regimens from its pediatric ART formulary, simplifying health workers’ and clients’ decision making around which drugs to use for treatment of HIV-infected children. At least 10 new effective pediatric HIV drugs from several ARV classes are currently in development. All but one are granules, dispersible tablets, or powder, which may ameliorate some of the difficulties currently associated with administration of ARV drugs to infants and young children. Particular interest in the field has focused on efforts to develop pediatric formulations of a novel integrase inhibitor (dolutegravir) and a new, less toxic formulation of tenofovir—both drugs have a better safety profile than their predecessors and can be administered once daily. Children accessing easily administered, effective pediatric ARV formulations, with better safety profiles, may be more likely to adhere to their treatment into adulthood.
EGPAF’s Work toward Ending AIDS in Children

**Pediatric HIV Testing, Care, and Treatment Programs**

In addition to advocating priority interventions to serve those affected by HIV and conducting research to expand scientific understanding of the disease and effective approaches to address it, EGPAF supports large-scale HIV prevention, care and treatment programs in 14 counties in sub-Saharan Africa and India. Throughout these countries, in networks of supported health facilities, EGPAF has worked to enable infant and child HIV testing within maternal and child health (MCH) and PMTCT platforms and has scaled up early identification and treatment of pediatric HIV in these and other health delivery settings (see Malawi article, page 13). This progress has enabled EGPAF to test more than 600,000 HIV-exposed children and to start more than 113,000 HIV-infected children on ART since EGPAF’s inception.19

Reflecting the success of PMTCT efforts, HIV-positive test results were found in only 4% of HIV-exposed infants that were tested for HIV in EGPAF-supported programs during 2014. In nine African countries where EGPAF supports pediatric HIV treatment programming, programs accounted for an estimated 10–15% of all children treated with ART in recent years (2013–2014).19

Overall in recent years, EGPAF-supported programs have identified more children with HIV infection through expanded program efforts. In 2014, EGPAF programs identified and linked 10,000 children less than 15 years of age to ART, most of whom were older, between ages five and 14. Access to HIV testing and ART initiation among infants have increased but still present challenges for our programs.19 As seen with other ART programs throughout sub-Saharan Africa, ART retention rates in all EGPAF-supported programs in 2014 ranged from 60% to 90%, with the lowest retention rates among the youngest cohort of children (less than 2 years old) and a progressive drop in retention from 12 and 48 months after initiation of ART.19
Expanding Access to Pediatric HIV Care and Treatment through Innovation and Technical Assistance

EGPAF supports the pediatric HIV care and treatment cascade through provision of technical assistance, work with national governments on policy development and implementation support, and a variety of capacity-building initiatives offered to health facilities and staff. EGPAF has advocated for increased prioritization of pediatric care and treatment in countries through involvement in national HIV technical working groups and through input on implementing national pediatric HIV treatment guidelines. Through these forums, EGPAF has assisted ministries of health in adapting the revised WHO guidelines on pediatric and adolescent HIV testing and treatment to each country’s context, updating algorithms for EID, and establishing criteria for ART initiation among children and for HIV testing of adolescents (see page 16 for an example of this work in Lesotho). EGPAF provides technical policy review and revision to ensure that policies on HIV testing and treating children (including those around task shifting and nurse-led ART initiation) and guidelines for ART initiation and monitoring (including recommendations around second-line and third-line treatment regimens) are up-to-date.

EGPAF also works with health programs and facilities to train and mentor health care staff, enabling all to offer high-quality pediatric HIV care and treatment services. We guide site-specific operational plans for scaling up pediatric HIV diagnosis, treatment, and retention based on needs assessments and prioritization exercises. EGPAF also offers various cadres of the health facilities uniquely tailored trainings and supportive supervision (developing and adapting curricula, training packages, and health worker job aids) that are informed by and in line with current national treatment guidelines to ensure quality provision of pediatric HIV services (see page 20 for an example of this work through our Project DELTA and page 22 for an example of comprehensive technical assistance in Uganda).

EGPAF will continue its support to ministries of health in scaling up adaptation and implementation of the WHO 2013 pediatric treatment guidelines. This support will entail technical assistance at the national, regional, and site levels (from policy development to health care worker capacity building). The work will involve implementation of best practices in pediatric treatment, including integration of HIV testing and counselling with other child health services such as nutrition wards, under-five clinics, immunization platforms, TB / opportunistic health sites (see page 13 for an example of this type of integration), and scale-up of psychosocial support initiatives such as EGPAF’s Ariel Club model (see page 12).

What is Next for EGPAF?

Point-of-Care Technology Expansion

Point-of-care technologies can help us reach a larger number of children with early testing and treatment. New point-of-care technologies are easy to use and less expensive than conventional methods of testing. Under a recently-awarded, UNITAID-funded project, EGPAF will expand access to point-of-care technologies within supported facilities to enhance testing at birth, 6 weeks, 9 months, and a rapid HIV antibody test at 18 months. This innovation offers numerous benefits, including decreasing loss to follow-up in the PMTCT testing cascade and increasing opportunities for initiating infants in need on ART within the first weeks of life. EGPAF will work with ministries of health in nine countries to introduce and scale up 650 point-of-care platforms and approximately 624,000–780,000 tests over three years.

This project will also research the possibility and effectiveness of point-of-care sample transport (where facilities without the technology can access the platform in nearby facilities), rotation of the platforms to different facilities, and referral systems. This project aims to increase early HIV diagnosis and initiation of infants on ART, resulting in increased infant survival in supported countries.
Our commitment to reach even more HIV-exposed and -infected children in order to match the targets set by the global community leads us to thoroughly evaluate the current status of our programming and to ensure continuing progress in pediatric HIV care and treatment in our supported countries. To ensure greater access for children in need of HIV treatment, we will support countries in developing and reaching treatment targets in line with new global targets, creating wider access to pediatric testing outside of the PMTCT cascade, ensuring the training of health workers in delivery of quality pediatric care and treatment, enhancing use of point-of-care technologies to encourage quick linkage to ART, and closely working with communities to offer a supportive environment for families and children affected by and living with HIV. This issue of Haba Na Haba highlights these activities across six supported country programs and their effect on improving the lives of children living with HIV.

The ACT Initiative: Scaling up Pediatric HIV Care and Treatment Programming

EGPAF was awarded a portion of the US$200 million ACT initiative that aims to double the total number of children receiving life-saving ART across 10 priority African countries over the next two years. EGPAF’s work under ACT will focus within eight supported countries: Cameroon, Kenya, Lesotho, Malawi, Mozambique, Tanzania, Zambia, and Zimbabwe. EGPAF’s scale-up of pediatric care and treatment services under ACT began in June 2015.

Accelerating Access to Second- and Third-line ART for Children

Programmatic scale-up in response to recent global HIV treatment targets is intended to significantly increase the number of HIV-infected children and adolescents initiated on ART. As this number increases, a growing number of treatment-experienced, HIV-positive children and adolescents failing first- or second-line treatment is to be expected. In 2014, Janssen Pharmaceuticals launched the New Horizons Advancing Pediatric HIV Care Initiative in collaboration with EGPAF and the Partnership for Supply Chain Management. Built from a pediatric treatment donation program, New Horizons aims to create a framework for strengthening health systems to support national HIV/AIDS programs in the management of treatment-experienced children and adolescents with donations of second- and third-line treatment regimens, which can be prohibitively expensive for African countries, as well as provider training and mentoring on drug use. Six countries have joined the program since 2014: Kenya, Lesotho, South Africa, Swaziland, Uganda, and Zimbabwe. Within these countries, EGPAF will collaborate with New Horizons to increase capacity among health care providers to provide adolescent testing and treatment services, identification and management of ART failure, adherence support, and evaluation of resistance. The program also strives to promote facilitated peer-to-peer knowledge exchange to increase pediatric and adolescent care and treatment expertise. A pediatric HIV cohort monitoring system will be established to facilitate the central collection of data and analysis regarding treatment failure in children and adolescents and outcomes of second- and third-line ART.

Photo credit: Nigel Barker
Supporting Children and Adolescents in HIV Care and Treatment

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Technical directors help lead HIV and AIDS programs in each of EGPAF’s 14 supported countries. Annually, all EGPAF technical directors meet to share lessons learned and technical expertise. This year, the technical directors met in Swaziland and, while there, were given an opportunity to witness a best practice in pediatric HIV programming in action.

Ariel Clubs

At Dvokolwako Health Center in Swaziland, the technical directors met with 15 members of an adolescent HIV peer support group called Ariel Club. The group, developed and supported by EGPAF, is named after Ariel Glaser, the daughter of EGPAF’s founder, who lost her battle with AIDS in 1988. The Ariel Club at Dvokolwako has 85 members enrolled in two subgroups: preteens, ages eight through 12, and teenagers, ages 13 through 19. Teen leaders organize and facilitate monthly meetings on a rotating basis. All participants receive transportation vouchers and refreshments.

Support meetings begin with participants picking up their next allotment of ARV medications and meeting with a clinician. These clinic visits are then followed by games, group discussions on specific topics, group singing, and prayers. EGPAF staff members train skilled teen leaders in the curriculum and in discussion moderation. The curriculum teaches self-confidence, safe dating practices, safe sex, and the importance of adherence to treatment.

The technical directors met with the teenagers from the older age group to discuss the role of peer support groups in their lives. The adolescents informed the directors that retention in care and ART was influenced predominantly by family support and positive attitudes from health workers (listening attentively, educating appropriately, and being flexible and understanding). They indicated that Ariel Club helped them to deal with disclosure, acceptance of their own positive HIV status, and stigma. The peer group, they said, gives members the chance to know that they are not alone and can share with others their feelings and the challenges of living with HIV, without any judgment or hostility.

When asked how to improve the Ariel Club activities, adolescents recommended inclusion of sports activities, longer duration for group meetings, and more opportunities to attend the annual off-site Ariel Camp, which is currently offered to each participant only once. Specific requests included more time together, more camps, and good transportation to the camps.

Clinicians supported teenagers’ statements on the benefits of the club, particularly the positive effects the activities appear to have on adherence. The health workers suggested better scheduling of the club days and allocating more staff time to support them. Swaziland is conducting formal evaluations to measure adherence to treatment among attending children and adolescents.

Lessons Learned

Currently EGPAF supports 16 Ariel Clubs, or teen support services, across nine countries. Scale-up of these types of services (with potential upgrades including tracking of progress through use of monitoring tools, and revisions in scheduling and group activities) could result in further reach of their promising effects, such as improved ART adherence and retention in HIV services, into the lives of children and adolescents.
EGPAF began collaborating with local partners in 2001 to initiate one of Malawi’s first programs to provide PMTCT services. By 2006, EGPAF was supporting more than half (54%) of all PMTCT services available in the country. Today, EGPAF provides technical assistance for HIV services at more than 150 Malawian Ministry of Health (MOH) and faith-based facilities, district-level health system strengthening in seven districts, and capacity building of community organizations.19

Malawi has made great strides toward elimination of pediatric HIV, including development and early implementation of the 2013 WHO PMTCT guidelines recommending lifelong ART among all HIV-positive pregnant and breastfeeding women (Option B+), which has enabled a reduction of the number of new pediatric infections from 28,000 in 2001 to 11,000 in 2012. Accessing and treating the children who do become infected, however, has been more limited to date—with only 34% of children living with HIV in Malawi receiving ART in 2012, compared with 76% of adults.19 Although Malawi was an early implementer of the newly recommended WHO guidelines on pediatric treatment, currently too many children are being missed in the pediatric cascade in the country. To identify more HIV-positive children, link them to care, and initiate all who are eligible on ART, EGPAF-Malawi is introducing and scaling up pediatric HIV testing at key health service delivery access points outside of the PMTCT cascade.

EGPAF, along with the district health management team and the facility ART coordinator, formed a QI team to evaluate the cause of low pediatric HIV testing rates and to create informed strategies to implement improvements. This team determined that the gap in testing was largely a result of health care providers in these sites not prioritizing HIV testing in children. The QI team began rolling out QI activities in three phases, starting with the NRU in April 2014, followed by the pediatric ward in September 2014, with the under-five clinic slated for rollout in July 2015. The activities implemented in this phased rollout included (1) orientation of health care providers on guidelines for HIV testing and integration, (2) weekly mentorship and supervision, (3) allocation of an HIV testing and counselling provider as a full-time staff member in all service areas, and (4) availability of HIV testing kits in each of the three service areas.

Following implementation of the QI activities, the large majority of the children who were admitted to the NRU and the pediatrics ward were tested for HIV upon admission. Their status was recorded in the admission register, and all children with a positive HIV test result were listed in a separate register to ensure they were referred to the ART clinic that same day for initiation of treatment. The numbers of children registered and tested for HIV were collected and compared. The QI team reviewed the data monthly to identify and address challenges.

The First Step in Closing the Pediatric Treatment Gap: Scaling Up Provider-initiated Testing and Counselling at Key Health Service Delivery Points in Malawi

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Implementing Provider-Initiated Testing and Counselling in Mchinji

In early 2014, EGPAF–Malawi, in partnership with Malawi’s MOH and with funding from PEPFAR and the U.S. Centers for Disease Control and Prevention (CDC), started a site-level quality improvement (QI) plan at Mchinji District Hospital, a semi-urban government health facility serving a catchment area of more than 50,000 people. This plan aimed to introduce provider-initiated testing and counselling among all children accessing the hospital’s nutritional rehabilitation unit (NRU), pediatric in-patient ward, and clinic for children under five years of age (under-5 clinic).
Results

Prior to the QI initiative, from January to March 2014, no children were tested for HIV in the NRU. As shown in Figure 2, of the 52 children visiting the NRU in April–June 2014, 44 (85%) were tested for HIV. Seven children were identified as HIV-positive (16%), and 100% of those were initiated on ART. From April 2014 through February 2015, a total of 191 children were admitted to the NRU, and 176 (92%) were tested for HIV. Of those tested, 19 (10%) tested positive for HIV, and all 19 were started on ART.

Similar results were seen from phase two of the initiative, strengthening PITC in the pediatric ward, which began in September 2014. As a result of this intervention, the percentage of children who were tested for HIV in the pediatric ward increased from 0% in June, July, and August 2014 to 92% in February 2015 (see Figure 3). From September 2014 through February 2015, a total of 1,630 children were admitted to the pediatric ward, and 1,439 (88%) were tested for HIV. Of these, 11 (0.77%) tested positive for HIV and were started on ART.

FIGURE 2: Percentage of children registered in the NRU who were tested for HIV (January 2014–February 2015)

FIGURE 3: Percentage of children registered in the pediatric ward who were tested for HIV (June 2014–February 2015)
Challenges

One initial barrier was not having a dedicated space for HIV testing in the NRU and pediatric ward. In response, hospital management provided a room specifically for child HIV testing in both service areas. ART initiation for some children was delayed by one week because of a lack of dedicated health care workers to initiate treatment in the pediatric ward and because some nurses lacked confidence in initiating children on ART. The ART coordinator of the QI team gave additional training and ongoing mentorship to nurses in these settings to address challenges.

Lessons Learned

- Pediatric provider-initiated testing and counselling was conducted infrequently outside of antenatal care and maternity wards in Malawi prior to this initiative. Malawi is now shifting focus to ensure that pediatric care and treatment is also offered at all NRUs, pediatric wards, and under-five clinics to improve identification of HIV-infected children and more effectively initiate children living with HIV on treatment.
- Ensuring that provider-initiated testing and counselling is provided by health staff necessitates the identification and remedying of site-specific barriers (e.g., lack of space, test supply chain challenges, etc.).
- In our experience, the HIV-positivity rate was significantly higher in NRU than in the inpatient ward.

Next steps

EGPAF is supporting the roll-out out of provider-initiated testing and counselling to under-five clinics and will use experiences in Mchinji District Hospital to scale up provider-initiated testing and counselling in all 63 supported sites in Malawi.” In anticipation of the additional human resources that this scale-up will require, EGPAF is funding two local organizations to hire, train, and manage a minimum of 130 HIV diagnostic assistants for pediatric testing.

Reaching the 90-90-90 targets will not be possible without a dramatic increase in the number of children tested for HIV. The scale-up and strengthening of pediatric testing and treatment initiation in NRUs, pediatric wards, and under-five clinics is a necessary step in closing the pediatric treatment gap, bringing us closer to an AIDS-free generation.

EGPAF is currently working in Dedza, Mchinji, Mzimba North, Mzimba South, Ntcheu, Ntchisi, and Rumphi districts.
EGPAF has played a key role in expanding pediatric ART coverage in Lesotho, a country with approximately 37,000–41,000 children living with HIV, of whom 20,000 are in need of treatment under the 2013 revised WHO treatment guidelines. EGPAF is working with other program implementers alongside the MOH to continuously close the treatment gap in the country. Under EGPAF’s major five-year project funded by the U.S. Agency for International Development (USAID), known as Strengthening Clinical Services (SCS), which began in 2010, 4,400 new children have been initiated on ART. Under SCS, EGPAF has provided support to the MOH through work in various technical working groups and through the development of pediatric treatment–related strategic plans (including development and cost needs analyses of the PMTCT and pediatric AIDS elimination plan), guidelines, training materials, and job aids. EGPAF also provides direct support to facilities and health workers in the field of pediatric HIV through providing training on pediatric ART guidelines, mentorship, supportive supervision, and direct service delivery support.

Although Lesotho has made significant progress in advancement of ART in children, several factors have created challenges to universal pediatric ART coverage:

- Reoccurring commodity stock-outs, preventing HIV testing availability at health facilities.
- High rates of staff turnover and human resource shortages, resulting in staff often feeling unfamiliar or uncomfortable with administration of pediatric HIV testing and treatment.
- Poor tracing of infant–mother pairs due to several factors, including incorrect contact details given by mothers (likely in order to avoid identification as HIV-positive in their communities).
- Self-transfer to other facilities, leading program implementers to count women as defaulters in one setting, as they successfully receive services in another.
- Lengthy DNA PCR turnaround time at the National Reference Laboratory, delaying or even preventing timely initiation of ART.

As a key partner of the MOH in HIV clinical program implementation, EGPAF played a major role in addressing these challenges. By advocating for political priority of pediatric HIV treatment at the national level; providing training and mentorship of new doctors, nurses, and midwives on pediatric treatment enrollment; and working at health sites to integrate PMTCT and pediatric treatment within MNCH, EGPAF has significantly increased availability and national uptake of pediatric HIV testing, care, and treatment services. EGPAF strives to continuously ensure that HIV-exposed children are tested, using early infant testing (and retesting throughout the breastfeeding risk period, at 24 months postnatal, or both), initiated on treatment, and retained in care. Approaches have resulted in steady growth in the numbers of infants and young children being tested early and initiated quickly onto treatment over last five years (see Figure 4).

In 2014, following new guidance from the WHO recommending initiation of all HIV-positive children on ART, EGPAF worked closely with the MOH to revise the national pediatric ART
EGPAF-Lesotho is now implementing other initiatives to increase the identification of HIV-positive children, including community-focused testing campaigns (“Know Your Child’s Status” and “Know Your Sibling’s Status”) and integration of HIV testing into child nutrition centers. We are also linking newly identified HIV-positive children from these various interventions to treatment and ongoing clinical monitoring. EGPAF and the MOH will continue to work to ensure quality PMTCT and pediatric HIV care and treatment services in Lesotho.
KENYA
Long-Term Surveillance of Children on ART: Lessons Learned from a Cohort in a High-Prevalence Setting of Kenya

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EGPAF began its work in Kenya in 2000 with a small, privately-funded PMTCT initiative that has since grown into one of the largest HIV prevention, care and treatment programs in the country. EGPAF is a key partner of Kenya’s Ministry of Public Health and Sanitation and its Ministry of Medical Services. As of December 2014, EGPAF provided PMTCT services to more than 1.4 million pregnant women; provided ARVs to more than 65,000 pregnant women living with HIV to help prevent transmission; and started more than 156,000 individuals on ART, including more than 20,000 children under 15. EGPAF also has established counselling and psychosocial support groups for people living with HIV/AIDS at the facility and community levels. In August 2010, the CDC awarded EGPAF funding to launch a project titled Supporting the Implementation and Expansion of High Quality HIV Prevention, Care and Treatment Activities at Facility and Community Level in the Republic of Kenya, or The Pamoja Project, with a goal of increasing the access to and use of quality, comprehensive HIV prevention, care, and treatment services in 12 counties of Nyanza Province from September 2010 to September 2015. EGPAF’s Pamoja Project now supports improved implementation of comprehensive HIV prevention, care, and treatment services in 92 health facilities in the Homa Bay, Ndhiwa, Rachuonyo North, and Rangwe subcounties of Nyanza Province.

Data on long-term health outcomes and survival of HIV-positive children receiving ART in lower- and middle-income countries are scarce. Globally, HIV/AIDS program implementers strive to monitor HIV-exposed or -positive children only through the maternal-to-child HIV risk period. For children on ART, very little is known about their retention on treatment or their health and wellness throughout the rest of their lives.

Kenya implemented the 2013 WHO guidelines on pediatric treatment in June 2014, and produced and rapidly implemented HIV management guidelines throughout the country. From 2007 to 2013, Kenya saw a significant reduction (by 44%) in new HIV infections among children, indicating gains in PMTCT coverage.

However, ART for all children who live with HIV in Kenya remains elusive. Homa Bay County, where EGPAF provides support through its Pamoja Project, is home to the highest number of new HIV infections among children; 2,724 new infections occurred among children in 2013. Fewer than half (42%) of infected children were accessing ART in 2013.21 The Pamoja Project has been working diligently to expand pediatric ART coverage in this area. To inform successful pediatric HIV care and treatment programs in this high-risk setting, EGPAF–Kenya conducted a review of children on ART, to better understand factors affecting retention in ART and health outcomes of treated children.
Following Children in Homa Bay through the Treatment Cascade

In early 2014, Pamoja staff conducted a retrospective health chart review of HIV-infected children younger than 10 who had ever enrolled on ART to determine retention in HIV care and treatment, and health outcomes. Data were collected from patient ART registers from 92 EGPAF-supported health facilities. Pamoja staff abstracted data from ART registers and filled out cohort summary sheets, which were developed by the Pamoja team to collect information on treatment outcomes at six months, one year, two years, and three years after the initiation of ART. Indicators analyzed included (1) number of children on first-line and second-line ART, (2) number of children who switched to a second-line regimen, (3) number of children lost to follow-up (defined as missing appointments for more than three months), and (4) number of children who died. In June 2014, an additional assessment of pre-ART registers was carried out in order to determine the number of children younger than 10 eligible for ART under current national guidance and the total number of those actually receiving treatment.

Pamoja Cohort Analysis Results

From 2011 to 2014, 1,458 children younger than 10 were on ART in the 92 Pamoja Project sites (Figure 5). Of the total pediatric cohort from January 2011 through June 2014, a very high percentage of children on ART were retained on treatment on their first-line therapy (93%), a small proportion (1%) were on second-line therapy, 3% had died, and 3% were lost to follow-up. According to viral load monitoring data, about 70% of those age five or younger were virally suppressed, but this suppression rate slowly declined to 58% among adolescents aged 15–19.

FIGURE 5:
Overall ART registration status in 92 facilities from January 2011 to June 2014 (n = 1,458)

FIGURE 6:
Overall ART outcomes of children in cohort (n = 1,458) as of June 2014
Next Steps

- Based on these findings, Pamoja will work closely with the MOH to initiate the remaining 22% of children in need on ART in the 92 facilities by early 2015.
- The analysis underscored the need to intensify defaulter tracing efforts in order to better identify children lost to follow-up. Having accurate documentation of the caregiver’s contact information at ART enrollment is crucial.
- As children on ART grow into adolescence, there is a need to provide increased adherence, disclosure, and psychosocial support to both the children and their parents/caregivers. There is also a need to consider planning for informed transition into adult care.
- The surveillance of ART outcomes through use of viral load testing is necessary in order to ensure early identification of children failing first-line ART and to transition them in a timely manner to second-line regimens. This will be a priority of the Pamoja Project in the coming months and years.

Conclusion

This analysis showed a very high retention rate among pediatric patients younger than 10 in Kenya. As program implementers with a mission to end AIDS in children, EGPAF is committed to working closely with the MOH in order to ensure close monitoring of those children on ART, identification of HIV-positive children and linkage to care and treatment, and provision of ongoing adherence support and viral load monitoring to children on ART in Kenya.

Pediatric Care and Treatment under EGPAF’s Project DELTA

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In September 2013, EGPAF received the DELivering Technical Assistance (DELTA) award, a five-year global technical assistance award funded by the CDC. Through Project DELTA, EGPAF is providing comprehensive technical assistance, capacity building, and program implementation expertise for health activities supported by the Global Fund and PEPFAR. The award focuses on three program areas:

- PMTCT
- HIV care and treatment for adults
- HIV care and treatment for children

In the area of pediatric HIV care and treatment, EGPAF has undertaken assignments in several countries through Project DELTA, including in Uganda and Cameroon.

Uganda

Uganda is home to an estimated 177,000 children living with HIV. Of those eligible for ART in the country (under ART eligibility definitions set by the WHO’s 2010 guidelines), only 41% are currently receiving it, compared with 75% of eligible adults. In mid-2014, PEPFAR in Uganda requested that EGPAF provide technical assistance through Project DELTA to the Ugandan MOH. As a result, EGPAF is helping to improve identification of HIV-positive children through provision of high-quality pediatric HIV testing and counselling services and linkage of HIV-positive children to care and treatment.
In less than one year, EGPAF has undertaken several important activities in partnership with the MOH and other implementing partners. These activities have included (1) establishment of national, regional, and district targets for pediatric HIV testing and counseling and for linking HIV-positive children to care and treatment; (2) analysis of routine program data to help regions, districts, and facilities reach those targets; (3) creation of a pediatric-specific data dashboard that displays progress toward targets for care; (4) development of tools to support national implementation of HIV testing and counseling, and linkage to care; and (5) an assembly of national standard operating procedures for pediatric testing and counseling, and linkage of HIV-positive children to care and treatment.

Cameroon
Through Project DELTA, EGPAF is supporting Cameroon’s national effort to improve pediatric HIV outcomes. In this country, an estimated 54,000 children younger than 15 are living with HIV, with 34,500 in need of ART. EGPAF’s first activity through Project DELTA was to identify pediatric HIV curricula and tools already in use in Cameroon in order to recommend materials that could be adapted for use in health centers providing pediatric HIV services. EGPAF then developed a Cameroon-specific course on the management of pediatric HIV for health care workers. The course was validated and adopted by Cameroon’s MOH, and EGPAF staff held a training of trainers with a cadre of health workers in January 2015, with a rollout of trainings at the regional level to follow throughout the year. The goal is to train 200 workers in pediatric HIV in Cameroon by 2016. EGPAF will also help to establish four centers of excellence in pediatric HIV management. These will be existing health centers providing high-quality pediatric HIV services that are to be used as training centers, allowing trainees to be mentored in providing service. These centers will continue to build the capacity of health care workers in Cameroon.

Activities to be undertaken in 2015–16 under Project DELTA will continue to build capacity for pediatric HIV identification, treatment, and management in both Uganda and Cameroon, as well as in additional countries. Building upon the PMTCT continuum, efforts to identify HIV-infected infants will be bolstered in Lesotho, Malawi, Tanzania, and Uganda through various Project DELTA assignments. Lessons learned in individual countries will be leveraged and shared across EGPAF country programs.
At least half a million children worldwide will acquire tuberculosis (TB) each year, and more than 74,000 children die from the disease annually.\textsuperscript{23} The WHO estimates that TB and HIV coinfection among children in countries with moderate to high prevalence ranges from 10% to 60%. The diagnosis of TB in children, however, is often missed or overlooked due to nonspecific symptoms (not unlike symptoms related to a common cold or flu) and lack of effective diagnostics. Children with vulnerable immune systems — and in particular, those infected with HIV — are most at risk of contracting TB and dying from it.\textsuperscript{24}

There were an estimated 58,000 cases of TB and HIV coinfection in 2013 in Uganda, 3% of which affected children.\textsuperscript{25} In response, the MOH developed national HIV/AIDS treatment guidelines requiring client screening for TB at each facility visit, to ensure intensified TB case finding and effective HIV/TB comanagement. Scaling up TB case detection in children living with HIV, however, remains a challenge in the country due to limited availability of effective TB diagnostics.

The Xpert automated nucleic acid amplification test can detect both Mycobacterium tuberculosis complex DNA (MTC) and rifampicin resistance (RIF) within two hours of sputum sample collection. This on-site technology could increase TB identification and access to care for those most at risk. Xpert can detect up to 67% of cases missed by commonly used smear microscopy.\textsuperscript{24} This technology, however, is not widely available in Uganda. In 2013, only 37 sites in Uganda were using GeneXpert to identify TB.\textsuperscript{25}

Prioritizing Intensified TB Case Finding in Children

Scale-Up of Diagnostic Equipment. EGPAF focused on intensified TB case finding in both adults and children beginning in October 2013. By 2015, EGPAF directly supported 36 sites to offer intensified TB diagnostics in children in the southwestern region and equipped seven laboratories at these sites with GeneXpert machines to diagnose TB in adults and children through the USAID-funded Strengthening TB and HIV/AIDS Response in Southwestern Uganda (STAR-SW) project. These seven equipped facilities process samples from the 234 sites in the 13 district supported by STAR-SW.

Transport Solutions. For facilities not equipped with a GeneXpert machine, EGPAF developed an innovative transport system to ensure that TB test samples are delivered to and results returned from the laboratories in a timely manner. EGPAF hired and trained 13 full-time motorbike riders. These riders collect samples from peripheral sites, ensure their delivery to the nearest equipped laboratory, and return results back to the sites. The riders have been trained in care and transport of sputum samples for TB and blood samples for CD4 cell count and DNA-PCR, among others.

Training and Tools. Active assessment of children for TB is particularly challenging for health workers. To ensure health workers’ capacity to identify children infected with TB, job aids were developed and disseminated at the 36 supported sites. These job aids,
designed in collaboration with the MOH, include a five-question symptom screening tool. If a child answers “yes” to any question, a sputum sample is collected and an Xpert test is performed. Those with a positive result are immediately enrolled on ART or stabilized on TB treatment prior to initiation on ART, based on their general health condition.

EGPAF offered health workers at each of the 36 sites at least one on-site continuous medical education session on TB in children. These sessions enhanced clinicians’ awareness of TB and proper use of job aids and Xpert tools.

Results
Promising results have been observed following these efforts to scale up intensified TB case finding in children in our 13 supported districts. Screening of children has increased fivefold in the last three quarters of 2014, from 15 sputum samples collected and processed in April–June 2014 to 74 in January–March 2015 at the seven laboratories with GeneXpert machines in the region (Figure 7). Of the 74 samples in the January–March 2015 quarter, 64% were sputum samples collected from children coinfected with HIV. All children identified as infected with TB were linked to care and are currently on TB treatment, and all children coinfected with TB and HIV who were not previously enrolled in HIV care have been enrolled on ART.

Through prioritization, training, and availability of transport and equipment, health workers were better able to identify children with TB or HIV/TB coinfection and ensure fast access to treatment. Innovations such as these allow health care implementers to take a broader, more efficient approach to ensuring the overall health and well-being of children.

Next steps
• Identifying children with TB and HIV/AIDS is crucial to providing timely linkage to care and treatment. This EGPAF-supported program has proved successful in ensuring that more children are assessed with the TB diagnostics and linked to care to prevent TB-related morbidity and mortality.
• EGPAF now plans to scale up intensified TB screening in children at all 206 EGPAF-supported sites providing TB care in the region. This will necessitate an increased number of GeneXpert machines, recruitment and training of bikers, and scale-up of health worker trainings in the region.
Patricia Fassinou is a technical director in EGPAF’s Côte d’Ivoire program. She came to EGPAF in 2007 after years of experience as a pediatrician in Côte d’Ivoire. She now oversees coordination and implementation of a large-scale PMTCT and care and treatment program (addressing needs of both children and adults) in the country. Here, Dr. Fassinou shares her life and experiences in pediatrics and HIV program management.

What is your role at EGPAF?
I’m the director of the Djidja Project at EGPAF in Abidjan, Côte d’Ivoire. Djidja focuses on the implementation of HIV prevention, care, support, and treatment programs in Côte d’Ivoire. I ensure management, coordination, and implementation of program activities in geographical zones assigned to EGPAF by PEPFAR. We ensure strategic orientation, technical support, and training of EGPAF staff, MOH personnel, and local and regional/district health authorities and facilities.

From 2007 to 2010, I was the senior technical advisor for pediatric HIV care and PMTCT under Project HEART.

What first attracted you to the field of pediatric care?
At the beginning of my career, I wanted to provide assistance to families with HIV-infected children; I wanted to ensure these children were cared for and to teach families how to be a part of their children’s well-being.

“The greatest joy in my professional life has been to see those children I helped to test and treat grown into adults …”
In 1999, in Côte d’Ivoire, I was working as a pediatrician at the Yopougon teaching hospital in Abidjan. I was assigned to assist one physician in the management of the hospital’s HIV pediatric care center. It was the only HIV pediatric care center in the country at the time, and only one physician oversaw it. When that physician was not available, families couldn’t receive the care they needed. This situation was unacceptable for me. It was at that moment that I decided to commit myself to pediatric HIV care.

Are there any recent innovations in the field of pediatrics that you are excited about?

This year, Côte d’Ivoire adopted the revised 2013 WHO pediatric treatment guidelines, which will allow a greater number of children living with HIV to access ART. This increase in treatment coverage in my country has the potential to keep a much larger group of children in a healthy, robust status, thus limiting HIV-related morbidity and mortality. I think also implementation of Option B+ is an incredible innovation, which will further contribute to the elimination of pediatric HIV.

What do you see as EGPAF’s largest hurdle to overcome in pediatric care and treatment programming?

Sustainability of the HIV care programs implemented. Ensuring local ownership and defining strategies and activities to national governments, local stakeholders, and organizations is and should continue to be an important area of focus for us to ensure that our work has a lasting effect in the countries we support. This issue of sustainability is not specific to EGPAF but applies to all HIV program implementers heavily reliant on external financing. In-country resources and efforts have to be put in place to ensure continuous access to HIV prevention, care and treatment services.

What do you feel is Côte d’Ivoire’s greatest challenge to providing care to all vulnerable children?

As of today, the greatest challenge remains identification of HIV-infected children through provider-initiated HIV counselling and testing, and subsequent effective linkage to pediatric HIV care and treatment among those diagnosed with HIV. Low levels of HIV testing among children contribute to the low numbers of children initiated on treatment in our country.

What professional accomplishment are you most proud of in your work?

The greatest joy in my professional life has been to see those children I helped to test and treat grow into adults; there are quite a few children who were under my care who are now young adults. I wish there could have been even more.

I have been fighting against HIV and AIDS in my country for years. I can say now that I am also very proud of having been strongly involved in the development of a training curriculum and materials that trained more than 300 pediatric HIV care providers in Africa over the last 15 years.
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