

2019

# Pediatrics Advocacy Brief



ST. PAUL'S UNIVERSITY



UNIVERSITY OF CAPE TOWN  
IYUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD



PEPFAR-supported orphans and vulnerable children with their aunt and cousins in Mozambique (PHOTO: SARAH DAY SMITH)

## Introduction

On 17 November 2017, leaders of major pharmaceutical and medical technology companies, multilateral organizations, donors, governments, organizations providing or supporting services for children living with HIV, and other key stakeholders participated in a High-Level Discussion on Scaling Up Early Diagnosis and Treatment of Children and Adolescents. The meeting was convened by His Eminence Peter Appiah Kodowo Cardinal Turkson, Prefect of the Dicastery for the Promotion of Integral Human Development, with the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), the Joint United Nations Programme on HIV/AIDS (UNAIDS), and Caritas Internationalis, and in close collaboration with the World Council of Churches-Ecumenical Advocacy Alliance (WCC-EAA), the World Health Organization (WHO), and the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF).

In recognition of the urgency of making more optimal pediatric ARV formulations available in 2018 and beyond, the participants of the High-Level Dialogue agreed to the following good faith commitments to focus, accelerate, and collaborate on the development, registration, introduction, and roll-out of the most optimal pediatric formulations and diagnostics.

*“Faith-based organizations were there long before the United States President’s Emergency Plan for AIDS Relief and the Global Fund to Fight AIDS, Tuberculosis and Malaria. They have much to teach us as they are at the forefront of innovative and alternative service delivery models.”*

— DEBORAH BIRX,  
UNITED STATES GLOBAL AIDS  
COORDINATOR

*“Faith-based organizations have led the way in reducing new infections among children, and are now leading the way to ensure that all children with HIV receive treatment.”*

— MARK DYBUL,  
EXECUTIVE DIRECTOR,  
GLOBAL FUND TO FIGHT AIDS,  
TUBERCULOSIS, AND MALARIA

*“Despite tremendous global progress, many challenges remain, particularly in low- and middle-income countries, but also among poor and marginalized populations in high-income countries. Babies are still being born with HIV, adults and children cannot access the second- and third-line HIV medicines they need, and health infrastructure often lacks basic services, such as water and electricity. We must all be part of the story and part of the solution to delivering accessible, affordable care for our vulnerable brothers and sisters.”*

— CARDINAL PETER TURKSON,  
PRESIDENT, PONTIFICAL  
COUNCIL FOR JUSTICE AND  
PEACE, HOLY SEE

## Overview

In 2015, PEPFAR and UNAIDS launched a new initiative to strengthen the capacity of faith leaders and faith-based organizations (FBOs) to advocate for and deliver sustainable HIV responses.<sup>1</sup> In recent years, investments in preventing mother-to-child transmission (PMTCT) of HIV have been successful in reducing the number of children born with HIV; however, the diagnosis and treatment for children who are living with HIV remains a major challenge. In 2017 the number of children accessing treatment increased in some of the 23 focus countries of the *Start Free, Stay Free, AIDS Free* framework for action.<sup>2</sup> Through support from PEPFAR and UNAIDS, more babies are being born HIV-free and children already living with HIV have been able to remain AIDS-free throughout adolescence and into adulthood. However, fewer than half of the 2.1 million children living with HIV globally are accessing life-saving antiretroviral therapy (ART).<sup>3</sup> In many communities around the world, FBOs are key to providing HIV care services to children living with HIV as they progress through adolescence and young adulthood.<sup>4</sup> The faith-based partners with whom PEPFAR and UNAIDS work have been and will continue to be essential to keeping children living with HIV connected to care as they transition throughout adolescence and young adulthood because these partners represent the largest non-governmental provider of pediatric HIV services and because they are linked to local places of worship whose presence in local communities is not tied to outside funders. The faith-based partners working alongside UNAIDS and PEPFAR have identified a number of activities to reach the global goal of ending the AIDS epidemic by 2030.<sup>5</sup>

## The Challenge in Front of Us

Religiously-motivated stigma regarding HIV may lead to denial and discrimination, preventing children and adolescents from receiving the critical care they need. Without treatment, HIV progresses rapidly and is often fatal in infants and children – almost 75% of untreated, HIV-infected children will die by their fifth birthday.<sup>6</sup> Understanding and addressing stigma while also expanding opportunities for early diagnosis and treatment of children by maximizing the resources of faith-based pediatric HIV providers are critical for preventing HIV transmission, disease progression, and death. To address this challenge, the UNAIDS/PEPFAR Faith Initiative worked with Caritas Internationalis to host a series of meetings with senior leaders from government, donors, civil society, and the private sector. Participants established a plan with 41 commitments to focus, accelerate, and collaborate on the development, registration, introduction, and roll-out of the most optimal pediatric formulations and diagnostics to increase the numbers of children on antiretroviral therapy.

## Roles of PEPFAR and UNAIDS

In response to the goal of ending the AIDS epidemic by 2030, UNAIDS and PEPFAR are now leading the *Start Free, Stay Free, AIDS Free* initiative. The initiative establishes two ambitious targets to address pediatric HIV: 1) “to elevate and amplify key initiatives that are already accelerating the progress for children, adolescents, and young women,” and 2) “eliminate new infections among children by initiating pregnant women living with HIV on lifelong antiretroviral therapy and ensuring that breastfeeding mothers are retained in care during the breastfeeding period.”<sup>2</sup> Because FBOs are the largest providers of pediatric HIV services outside of government programs and because they are essential organizations in the social fabric of local communities, efforts to strengthen and expand partnerships with FBOs are critical. Named most frequently as a trusted community resource, FBOs provide approximately 25% of treatment visits for children living with HIV/AIDS, including children who are currently on ART.<sup>7</sup> Those contributions extend beyond clinical treatment to include social support. However, most of these social support services are undocumented because they are carried out by congregational communities in local contexts that are not part of broader national programs or health systems.<sup>6</sup>

Because of the essential contributions of their faith-based partners, UNAIDS and PEPFAR are committed to strengthening their collaboration to support faith-based initiatives to address pediatric HIV and to measure, monitor, and maximize the impacts of FBOs on pediatric HIV.<sup>7</sup>

## Snapshots of Success

UNAIDS and PEPFAR’s existing partnerships have contributed to increasing access to care, advocated for children and adolescents living with HIV, and engaged faith and community leaders on how to better identify and care for children living with HIV and AIDS. Some of the current partnerships and programs are highlighted here:

### 1. Collect, analyze, and disseminate data

The academic consortium of the UNAIDS/PEPFAR Faith Initiative is collecting data in a number of high HIV prevalence countries on the impact of faith-based care providers, and to map geospatial locations of faith-based facilities and the pediatric HIV services they provide.<sup>8</sup>

Mapping the location of these facilities and documenting their services are not only useful for the communities in which they exist, but also for the global community to identify gaps, build capacity in high prevalence areas, and support linkages to care between community and clinical programs. Such efforts are essential for reaching children at risk for and currently living with HIV.

## 2. Address stigma and discrimination

The World Council of Churches—Ecumenical Advocacy Alliance (WCC-EAA) developed and implemented the Frameworks for Dialogue methodology that establishes support and advocacy priorities through the development of community action plans to address HIV in local communities where the program was carried out. The 2015 Framework plans implemented in Kenya in 2015 were evaluated for impact and sustainability in 2017. With no additional outside sources of funding, local community leaders had maintained efforts to meet community objectives and committed to offer additional support to people living with HIV by committing to the *Leading by Example: Religious Leaders and HIV Testing Campaign* to challenge stigma and offer support to people living with or affected by HIV. Through such efforts, religious leaders in Kenya mobilized as Faith Pediatric AIDS Champions. In June 2017, these leaders launched pediatric HIV efforts that included advocacy in support of the 2018 UNAIDS treatment targets for children and adolescents, HIV testing in local faith communities and religious schools, and social media campaigns to provide positive messages of strength and compassion.

Saint Paul's University, a member of the academic consortium in Kenya, conducted interviews and focus group discussions to better understand the influence of religion on stigma and how faith-based health systems can minimize stigma and maximize support for children and adolescents living with HIV and AIDS. Findings from this research is being used to develop and implement a curriculum to equip FBOs and religious leaders to assess their policies and activities to ensure they reflect the needs and priorities of adolescents living with HIV. This information will also inform future activities in the *Framework for Dialogue* methodology.

## 3. Developing continuity of care throughout childhood, adolescence, and emerging adulthood

Nyumbani is an FBO that provides HIV primary care to over 4,000 children, adolescents, and young adults in informal settlements of Nairobi, Kenya. Nyumbani's Lea Toto project has developed a transitional program for children as they grow into adolescence. The project will prepare adolescents and young adults, aged 14-24, to transition from Lea Toto's pediatric HIV care services to adult care clinics run by other FBOs or government-run facilities. By establishing continuity of care, adolescents will be able to better manage their HIV infection and contribute to the strengthening of the local care system.

## 4. Scale-up and expand reach of treatment for children living with HIV

PEPFAR and UNAIDS, in partnership with Caritas Internationalis, have hosted a number of regional and national consultations with global partners as well as meetings at the Vatican to identify opportunities to expand reach and treatment of children living with HIV/AIDS, scale-up diagnostic and treatment tools, and engage national and local FBOs. These consultations included discussion on ways to make HIV treatment more suitable for children and make diagnostic tools more widely available for at-risk communities. In Kenya, Nigeria, Zimbabwe, and the Democratic Republic of the Congo, the PEPFAR/UNAIDS Faith Initiative co-sponsored consultations in collaboration with each nation's HIV coordinating bodies. These consultations brought together national faith partners to strengthen coordination between FBOs and other partners in the national AIDS response and to develop a national faith action plan. In Kenya, the WCC-EAA and the Kenya chapter of the International Network of Religious Leaders Living With or Affected by HIV/AIDS (KENERELA+) have worked closely with the National AIDS Control Council and its Faith-Based Organization Steering Committee, to implement faith advocacy activities to scale up testing and treatment for infants, children, and adolescents.

## Opportunities Moving Forward

UNAIDS and PEPFAR, in coordination with numerous global partners, have been able to make progress in addressing the challenge of pediatric HIV and AIDS. Nonetheless, there is still a long way to go to reach all the children in need and attain the goal of ending the AIDS epidemic by 2030. Faith-based partners have been and will continue to be powerful contributors towards achieving this goal through a number of opportunities:

### 1. Increased collaboration between FBOs and local and national governments

For continued success in addressing pediatric HIV and AIDS, there must be increased collaboration between FBOs and local and national governments. Through collaboration, communication will improve about best practices that can be replicated. Additionally, building networks between FBOs and governments will allow for children and adolescents to transition more smoothly into adult HIV care services. To support these efforts, the UNAIDS/PEPFAR Faith Initiative in convening national level consultations in other countries with high HIV prevalence to establish national-level action plans, implement mechanisms to coordinate interfaith responses, and establish agreements between FBOs, civil society partners, and national and local governments.

### 2. Establish and strengthen platforms of national FBOs

By providing FBOs with platforms to engage with their communities, leaders can be mobilized as advocates and speak out against discrimination. This also includes developing and disseminating a variety of pediatric HIV messages targeted to various platforms and audiences.

### 3. Engage local communities, clergy, and clinics

Moving forward, partners will be working to develop and disseminate sermon guides; create call-to-action and letter templates for child-advocates; develop curricula on the science of HIV, stigma management, and ART; and create or strengthen partnerships between community-based FBOs, local faith communities, and faith-based clinical providers to create a continuum of care to retain children living with HIV in care as they grow into adolescence.

# PEDIATRICS ADVOCACY BRIEF

## SUPPORTING DATA

Figure 1: UNICEF Children and AIDS Statistical Update



**SUB-SAHARAN AFRICA  
ACCOUNTS FOR ABOUT 9 IN  
10 OF WOMEN AND CHILDREN  
LIVING WITH HIV**

### Most children lack testing and treatment

While pediatric HIV prevention is a real success story, pediatric HIV testing and treatment is lagging.

In 2016, only 43 percent of HIV-exposed infants were treated within the recommended first two months of life. Similarly, only 43 percent of the 2.1 million children living with HIV around the world received antiretroviral therapy (ART). Without timely treatment, mortality in children with HIV is very high. There were 120,000 children who died of AIDS-related causes in 2016.

In order to end AIDS in children, the remaining 57 percent of children (1.2 million) who are not on treatment need to be identified and started on lifelong treatment as a matter of urgency. Novel targeted approaches such as HIV testing in hospitalized children and in nutrition centres and using point-of-care virologic tests which can provide results 'while you wait' may help to identify these children and enable rapid initiation of treatment.

**43%**  
OF CHILDREN LIVING  
WITH HIV ARE  
RECEIVING ART

**18 CHILDREN**  
ARE INFECTED WITH  
HIV EVERY HOUR

Source: <https://data.unicef.org/resources/children-aids-statistical-update/>

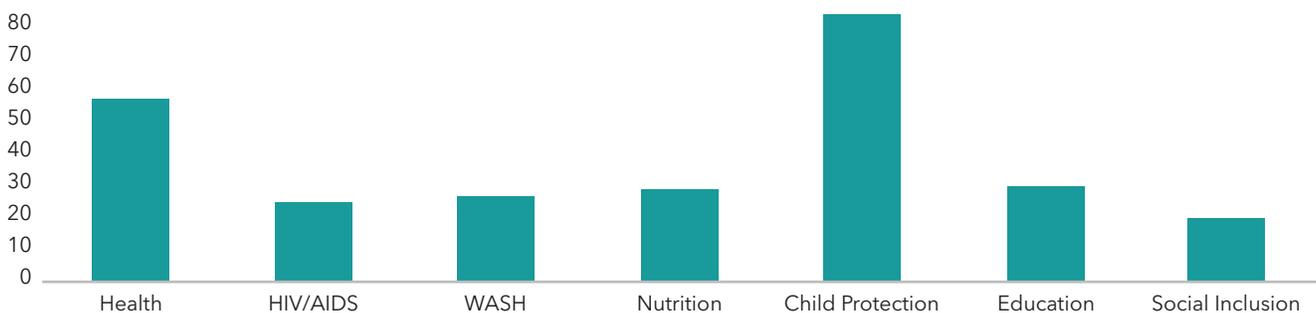
Figure 2: Pediatric HIV treatment in three Kenya counties: Homa Bay, Nairobi, and Turkana

County	Total on ARTs [DUPLICATE VISITS]	Number of FBOs	ART visits provided by FBOs
<b>Homa Bay</b> 19,370 CHILDREN LIVING WITH HIV	41,246	20*	20.1%
<b>Nairobi</b> 12,894 CHILDREN LIVING WITH HIV	41,519	44*	48.9%
<b>Turkana</b> 5,736 CHILDREN LIVING WITH HIV	7,728	2*	54.9%

**Total currently on ARTs = Males under 15, Females under 15, Under one year**

\* Number of FBOs that provide pediatric HIV services

Figure 3: UNICEF engagement by method and number of countries



Source: UNICEF (2015). A Global Mapping: UNICEF Engagement with Religious Communities. Communities Civil Society Partnerships. Division of Data, Research and Policy.

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8. For information on these efforts, see <http://ihpememory.org/kenya-overview/kenya-county-data/>

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## Key Messages

Faith based organizations (FBOs) are important for sustained, comprehensive pediatric HIV efforts. For example:

1. FBOs offer unique resources to children living with HIV to support a continuum of care through childhood, adolescence and emerging adulthood.
2. Faith-based health facilities and clinics are embedded in local communities alongside places of worship and extensive community religious networks. Together, these varied FBOs are trusted, essential partners making a difference across the world, especially in rural and geographically isolated areas. These FBOs are essential in global efforts to address the pediatric HIV epidemic and support children living with or infected by HIV.
3. The engagement of religious leaders as gatekeepers to community opinion can be influential in mobilizing parents to take up HIV testing for themselves and their children.

## Overview

While there has been great success in preventing mother-to-child transmission (PMTCT) of HIV, the diagnosis and treatment for children living with HIV is lagging behind global targets. Reaching children with age-appropriate, optimal HIV services remains a high priority because fewer than half of the 2.1 million children living with HIV globally are accessing life-saving antiretroviral therapy (ART) used to fight HIV disease progression.<sup>1</sup> Around the world, FBOs provide HIV services to children living with HIV as they progress through adolescence and young adulthood and are a key partner to scaling up access to testing and treatment for children.<sup>2</sup>

## The Contributions of Faith-Based Partners in Caring for Children Living with HIV

Almost 75% of children infected with HIV will die by their fifth birthday without access to medication.<sup>2</sup> Named most frequently as a trusted community resource, FBOs provide approximately 25% of all treatment visits across the globe for children living with HIV/AIDS, including children who are currently on ART.<sup>3</sup> An analysis of pediatric service provision in Kenya reveals that FBOs provide 79% of all patient visits in Nairobi County (the county with the highest number of HIV cases) in which children living with HIV receive medications.<sup>4</sup>

### PEPFAR Orphans and Vulnerable Children Data, 2017

13.4 Million	95%	2.1 Million	2 Million
Over 13.4 million children are living without one or both parents due to AIDS.	About 95% of children directly affected by HIV/AIDS live with their extended family.	2.1 million children are living with HIV/AIDS, but less than half have access to treatment.	Nearly 2 million babies have been born HIV-free with PEPFAR support.
			

Source: <https://www.pepfar.gov/priorities/children/index.htm>

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## Partnerships Between FBOs, PEPFAR, and UNAIDS

The Joint United Nations Programme on HIV/AIDS (UNAIDS) and the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) have developed strong partnerships with FBOs over many years. These partnerships have been vital in increasing access to care, advocating for children and adolescents living with HIV, and engaging faith and community leaders on approaches to better identify and care for children living with HIV and AIDS. Programs offered through these partnerships include:

### 1. *Strengthening the engagement of FBOs in the pediatric HIV response*

Caritas Internationalis has hosted regional and global consultations to build partners' capacity to care for children living with HIV/AIDS, scale-up diagnostic and treatment tools, and engage national and local FBOs to advocate for ongoing support of pediatric HIV care. As follow-up activities to those consultations and with the support of its national members, Caritas Internationalis is implementing sub-national trainings for religious leaders in Nigeria and the Democratic Republic of the Congo aimed at reducing stigma and discrimination against children living with HIV as well as serving as a bridge between identified health centers and their congregations.

### 2. *Intensifying commitment to end AIDS among children and adolescents*

Caritas Internationalis collaborated with the Dicastery for the Promotion of Integral Human Development and other global partners to host a series of meetings with senior leaders from government, multilateral organizations, donors, civil society, and the private sector. Participants established a plan with 41 commitments to focus, accelerate, and collaborate on the development, registration, introduction, and roll-out of the most optimal pediatric formulations and diagnostics.

### 3. *Scale-up and expand reach of treatment for children living with HIV*

In Kenya, the World Council of Churches—Ecumenical Advocacy Alliance (WCC-EAA) and the Kenya chapter of the International Network of Religious Leaders Living With or Affected by HIV/AIDS (KENERELA+) have established an interfaith FBO Steering Committee which is mobilizing faith advocacy activities to scale up testing and treatment for infants, children, and adolescents. In addition, in several countries, the WCC-EAA works with Faith Pediatric HIV Champions who are committed to speak out and engage with key stakeholders in support of the rights of children and adolescents living with HIV and to utilize congregational platforms for outreach to encourage community members to make full use of services for children living with HIV.

### 4. *Engage local communities, clergy, and FBOs*

Faith-based partners have developed and disseminated sermon guides and supported advocacy efforts by creating call-to-action letter templates that can ensure timely responses by community stakeholders and religious leaders on pediatric HIV. These partners have also created audience-specific curricula on HIV prevention and treatment and on effective models for managing stigma to engage local communities on the clinical and social issues impacting pediatric HIV efforts. In June 2016, on the Day of the African Child, the WCC-EAA launched a Call to Action – *Act Now for Children and Adolescents Living with HIV* – in which religious leaders and representatives of FBOs call on governments to take action in: funding pediatric HIV national plans; promoting early diagnosis, optimal pediatric formulations, and access to TB drugs; eliminating stigma and discrimination; and addressing food insecurity. Christian and Islamic Khutbah guides on pediatric HIV were also launched at the Call to Action. Orthodox sermon guides on PMTCT and gender-based violence were developed in Ethiopia as an outcome of the Framework for Dialogue between religious leaders and people living with HIV.

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