Case Study on Improving HIV Testing and Services for Children Orphaned or made Vulnerable by HIV (OVC)

APPROACHES OF THE LEA TOTO AND APHIAplus *NURU YA BONDE* PROGRAMS IN KENYA

Important note: the photographs in this publication are used for illustrative purposes only; they do not imply any particular health status on the part of any person who appears in the photographs.

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List of Acronyms

APHIA	AIDS, Population and Health Integrated Assistance
ART	Antiretroviral therapy
CCC	Comprehensive care clinic
CHEW	Community health extension worker
CHV	Community health volunteer
COGRI	Children of God Relief Institute
FAIR	Family AIDS Initiative Response
GBV	Gender-based violence
GoK	Government of Kenya
HTS	HIV testing and services
KCIU	Kenya Council of Imams and Ulaama
KNH	Kenyatta National Hospital
MoH	Ministry of Health
MoEACLSP	Ministry of East African Community, Labour and Social Protection
M&E	Monitoring and Evaluation
NASCOP	National AIDS and STI Control Program
NGO	Non-governmental organization
OLMIS	OVC Longitudinal Monitoring Information System
OVC	Orphans and vulnerable children
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PITC	Provider-initiated testing and counseling
PMTCT	Prevention of mother-to-child transmission
TB	Tuberculosis
USAID	United States Agency for International Development

Introduction

PURPOSE

In spite of the dramatic success of HIV treatment programs around the world, children remain under-tested, and are thus denied access to lifesaving treatment. The UNAIDS 2015 Progress Report states that in 2014, only 49% of all HIV-exposed infants in the Global Plan 21 priority countries [1] received a virologic test to determine their HIV status within the first two months of life, as recommended by the World Health Organization. The same report reveals that only 31% of children living with HIV were receiving the antiretroviral treatment they needed.[2]

Childhood HIV infection is especially complex in terms of case finding, diagnosis and treatment – requiring specific approaches depending on whether infection was vertically or horizontally acquired – and whether it is suspected at birth, during early or middle childhood or adolescence. Like adults with HIV, children and adolescents living with HIV face a multitude of practical barriers in achieving viral suppression, but they are perhaps even *more* constrained, subject not only to the wide range of household-level, developmental and societal barriers, but by their reliance on caregivers.

Improved case finding of HIV-infected infants, children and adolescents is urgently needed to maximize pediatric treatment coverage, reduce rates of HIV-related infant and child mortality, and optimize outcomes and prevent future spread as children mature to adulthood.

Programs for orphans and vulnerable children (OVC), through their community presence and unique relationships with caregivers and children, are especially well placed to promote and facilitate the entire HIV care and treatment cascade throughout a child's development, using age-appropriate approaches. These programs have a long history of building community capacity to protect children through awareness and self-management of child protection threats and solutions, increased male involvement in parenting and child health, reducing stigma and discrimination, and providing social support to children living with HIV and their families.

Acknowledging that OVC are at increased risk for HIV infection,[3] and in alignment with PEPFAR technical guidance, OVC programs aspire to ensure that all individually registered OVC beneficiaries have a known HIV status. Over the past four years, many programs worldwide have scaled up efforts to apply family-centered approaches to promote and facilitate testing, treatment linkages and adherence support for children and adolescents, while encouraging other household members, including fathers, to also know their HIV status and access relevant treatment and other services.

In response to a request from the Office of HIV and AIDS (OHA) at USAID, 4Children was asked to develop a set of case studies to promote learning from OVC programs that have successfully designed interventions and approaches to increase HIV testing and services (HTS) for children.

METHODOLOGY

Between April and September 2016, 4Children documented efforts by OVC programs to link children to testing and treatment in three countries; these included Pact's Yekokeb Berhan program in Ethiopia, the World Education Inc./ Bantwana Expanded IMPACT Program in Zimbabwe and COGRI's Lea Toto program and the FHI360 led APHIAplus program in Kenya. For each program, documentation efforts included a comprehensive desk review (project, country-specific and global reference documents), meetings with the USAID OVC technical officer, site visits and key informant interviews or focus group discussions with program staff, various community workers, health sector staff, caregivers and children. Program staff reviewed the draft case studies and provided further input and clarifications.

The Setting

COUNTRY BACKGROUND

Kenya overlies the East African Rift, covering a diverse and expansive terrain that extends roughly from Lake Victoria to Lake Turkana and continuing farther southeast to the Indian Ocean. It shares its borders with Tanzania, Uganda, South Sudan, Ethiopia and Somalia. Kenya's capital city, Nairobi, is a regional commercial hub. The economy of Kenya boasts the largest GDP in East and Central Africa. Kenya has an estimated population of 46 million, with more than 41% of the population under the age of 15.[4]

In 2010, following the 2007-08 election protests, the constitution was promulgated, leading to a new dispensation order. The new constitution has delegated more power to local governments, abolished the historical provincial administration, and transformed its districts into 47 semi-autonomous counties, each headed by a governor.

From a low point following disputed elections in 2007 and the global financial crisis of 2008, Kenya's economy and governance have improved. The country has averaged 5.5% growth since 2010, and in 2014 it became a middle-income country, signaling the availability of significantly greater domestic resources.[5] Yet Kenya continues to be plagued by persistent internal conflicts, vulnerability to terrorism and insecurity and climatic risks. All of these factors, along with harmful social norms and gender inequality, threaten the country's progress and undermine the equitable realization of children's rights. This is particularly true in northern, northeastern and coastal areas of the country and in growing informal urban settlements.

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1   Angola, Botswana, Burundi, Cameroon, Chad, Côte d'Ivoire, the Democratic Republic of the Congo, Ethiopia, Ghana, Kenya, Lesotho, Malawi, Mozambique, Namibia, Nigeria, South Africa, Uganda, the United Republic of Tanzania, Swaziland, Zambia and Zimbabwe.
2   Joint United Nations Programme on HIV/AIDS (UNAIDS). 2015 Progress report on the Global Plan towards the elimination of new HIV infections among children and keeping their mothers alive.
3   PEPFAR (2012). *Guidance for Orphans and Vulnerable Children Programming.* Available at: http://www.pepfar.gov/documents/organization/195702.pdf
4   Government of Kenya, UNICEF and Global Affairs Canada (2015). *Taking child protection to the next level in Kenya.*
5   Government of Kenya, UNICEF and Global Affairs Canada (2015). Ibid.

HEALTH AND SOCIAL WELFARE CONTEXT

Responsibility for service provision to OVC is shared between the Ministry of East African Community, Labour and Social Protection[6] (MoEACLSP); the Ministry of Health (MoH); the Ministry of Interior and Coordination of National Government; and the county governments. The 2013 situation analysis of Kenya's social welfare workforce[7] identified significant capacity gaps, mainly in terms of trained personnel, causing the bulk of direct service to OVC to be devolved to the volunteer cadre. Fortunately, Kenya's universities and diploma training programs offer relevant courses and continue to professionalize this critical workforce.

Kenya has made steady progress in addressing its health needs over the past 20 years, leading to the achievement of several Millennium Development Goals, specifically, reduced child mortality, near universal primary school enrollment and narrower gender gaps in education.[8] Decentralized health care and free maternal health care at all public health facilities will improve health care outcomes, and lead to the development of a more equitable health care system.

Results from the 2014 Kenya Demographic and Health Survey (KDHS) show a decline in the total fertility rate from 4.9 births per woman in 2003 to 3.9 in 2014, a one-child decline over the past ten years, and the lowest total fertility rate ever recorded in Kenya. The decline in fertility accompanies a marked decline in infant and child mortality. Total under-five mortality declined from 115 to 52 deaths per 1,000 live births in that same time frame, and the percentage of births attended by a skilled provider increased by 20% between 2003 and 2014.[9]

KENYA'S HIV EPIDEMIC AND RESPONSE

Kenya's HIV epidemic is described as generalized with an average HIV prevalence of 5.9% among the general adult population,[10] a significant decline from a high of 10.5% in the 1990s. New HIV infections (all ages) continue to decline, especially among children ages 0-14 years (from 12,000 annually in 2013 to 6,600 in 2015).[11] By 2015, nearly 900,000 persons living with HIV were receiving antiretroviral therapy (ART), including 71,547 children ages 0-14 years.[12] This translates to ART coverage of 58% among adults and 73% for children ages 0-14 years. However, only 56% of women and 66% of men have comprehensive knowledge about HIV prevention and transmission.[13]

Women and girls remain disproportionately affected, with 21% of all new HIV infections occurring among females ages 15-24. In 2014, Kenya introduced Option B+ to ensure that all pregnant women with HIV are initiated on ART, and remain on lifetime HIV treatment to protect their own health and that of their future children. In 2015, 74% of pregnant women living with HIV received effective ART to prevent the mother-to-child transmission of HIV.[14]

HTS has been a prominent feature of the HIV response in Kenya.[15] The country has adopted a number of strategies including provider-initiated testing and counseling (PITC), outreach testing and counseling and home-based testing and counseling (HBT), as well as the integration of HTS in antenatal care, sexually transmitted infection STI clinics and sexual and reproductive health services. As a result, there has been dramatic progress in terms of the number of people getting tested annually for HIV from 860,000 in 2008 to 6,400,000 in 2014.[16]

Mapping the way forward, Kenya's ambitious National Plan for Accelerating HIV Care and Treatment 2015-2017 aims to have 90% of infected individuals identified, 90% of those identified receiving ART, and 90% of those on ART achieving viral suppression by 2017.[17] In July 2016, the Kenya Ministry of Health (MoH) and National AIDS and STI Control Program (NASCOP) released new HIV treatment guidelines[18] that call for treatment of *all* persons living with HIV provided that the individual is willing and ready to adhere to follow-up recommendations.

> *Kenya's July 2016 HIV treatment guidelines call for treatment of all persons living with HIV, regardless of CD4 count or health status, preferably within two weeks of confirmation of serostatus.*

However, rational access to HIV treatment is still extremely challenging. Health work force challenges associated with numbers, cadres, competencies, deployment and distribution continue to plague the health system, and are a key barrier to accelerated HIV service delivery. Although ART is widely available and can be accessed at private and public facilities,[19] the majority of the comprehensive care clinics (CCCs) are located in counties with high HIV burden, making access to testing and treatment difficult in the counties with low burden.[20]

Decentralization of services is still a work in progress. Sixty percent of facilities providing ART are health centers and dispensaries, but the majority of clients (70%) are still managed in primary (district-level) and secondary (provincial-level) hospitals. There are currently seven

6   Until recently known as Ministry of Gender, Children and Social Development
7   Luisa López, L. Guyer and P. Mutie (2013). *Situational Analysis: Kenya's Social Welfare Workforce*. USAID/CapacityPlus
8   http://www.worldbank.org/en/country/kenya/overview
9   Kenya National Bureau of Statistics and ICF International (2015). *Kenya Demographic and Health Survey 2014*.
10   Kenya Ministry of Health, NASCOP (2015). *The Kenya HIV Testing Services Guidelines*
11   UNAIDS (2016). Prevention Gap Report: http://www.unaids.org/sites/default/files/media_asset/2016-prevention-gap-report_en.pdf
12   UNAIDS (2016) *Prevention Gap Report*:http://www.unaids.org/sites/default/files/media_asset/UNAIDS_Gap_report_en.pdf
13   Kenya National Bureau of Statistics and ICF International (2015). *Kenya Demographic and Health Survey 2014*.
14   Kenya Ministry of Health NASCOP (2015). *National Plan for Accelerating HIV Care and Treatment 2015-2017*.
15   AVERT (2016). *HIV and AIDS in Kenya*: http://www.avert.org/professionals/hiv-around-world/sub-saharan-africa/kenya
16   National AIDS Control Council of Kenya (2014) Kenya AIDS Response Progress Report 2014: Progress towards Zero.
17   Kenya Ministry of Health, National AIDS Control Council (2014) *National AIDS Strategic Framework 2014/2015-2018/2019*.
18   MoH, NASCOP (2016). *Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection in Kenya*.
19   National AIDS and STI Control Programme (NASCOP), Kenya (2014). Kenya AIDS Indicator Survey 2012: Final Report
20   MoH, NASCOP (2015). Ibid.

laboratories in the country that provide viral load testing services.[21] Early infant diagnosis testing is conducted through a national referral network bogged down in inefficient systems for sample transportation and return of results, resulting in long turnaround times. The health management information system is still largely paper-based, resulting in large workload, inaccuracies and lack of timely, accurate data to inform decision-making. Treatment access barriers include stigma, discrimination and lack of information on service availability.

BARRIERS TO HIV TESTING FOR CHILDREN

Until the 2012 Kenya AIDS Indicator Survey (KAIS),[22] HIV prevalence surveys did not provide estimates for HIV infection in children. In the 2012 survey, the prevalence in children 18 months to 14 years was estimated at 0.9%. In 2015, UNAIDS[23] estimated that between 81,000 and 120,000 children under 15 years of age were living with HIV.

The 2012 Kenya AIDS Indicator Survey report also states that among children of people living with HIV (PLHIV), only 45.4% had ever been tested for HIV. A study conducted at Kenyatta National Hospital in 2015 showed that – even with a robust active referral intervention – PLHIV enrolled in treatment are still extremely reluctant to have their children tested. Common reasons cited by caregivers in this study included having children who lived far away or wanting to test children at another location (27%), wanting to return later or being in a hurry (35%), wanting to consult with/disclose to/bring their partner (20%), or wanting testing outside of a research setting (9%).[24] The same study also revealed that more than 35% of adults in HIV treatment had children over 12 years of age who had never been tested. In 2013, a quarter of all Kenya's AIDS-related deaths occurred among children and adolescents 0-19 years old.[25]

Treatment coverage among children has, however, significantly improved since 2013. By 2015, 71,547 children ages 0-14 years were on treatment, a coverage rate of 73%.[26] The National Plan encourages counties to give focused attention to underserved populations, including children, adolescents and youth, and suggests several high-yield intervention packages depending on the HIV burden of the county.[27]

Caregivers, community volunteers and program staff concurred that fear of discrimination is still a barrier to considering HIV testing for a child.[28,29] Discomfort and cultural taboos associated with talking about sex (an unavoidable component of most HIV conversations) often result in delays and heightened awkwardness. Family and cultural norms, such as household power dynamics and gender-

based violence, often deter female caregivers from acting on the child's behalf. A child's HIV-positive test result can be very risky for mothers, since it is assumed the virus was transmitted by the mother, who is thereafter considered to be immoral and often rejected by her husband. A recent study in Kenya concluded that interventions addressing individual-level barriers, such as logistical challenges, testing before children become symptomatic, allaying parents' fears about child suffering, addressing parents' guilt or blame, and providing support to cope with a child's diagnosis, care, and disclosure, are needed to increase uptake of testing.[30]

Of equal significance, the majority of children living with HIV have not been informed of their status. Parents, caregivers and service providers are reluctant to initiate disclosure conversations for fear of causing distress to the child, triggering the inadvertent disclosure of their own status, or often simply because they lack confidence in their own skills to manage the process effectively. In a 2012 study at Kenyatta National Hospital, only 19% of caregivers of children ages 6-16 years reported that their children had been informed of their HIV diagnosis, even though most children were on treatment and had made repeated clinic visits that provided several opportunities for disclosure.[31]

The Case Study

INTRODUCTION

In August 2016, case study interviews were held with program managers and staff, community workers, caregivers, youth and children and facility-based workers engaged with two USAID-funded programs in Kenya: Lea Toto in Nairobi, and APHIAplus in Nakuru County, a heavily populated agricultural area 90 kilometers northeast of Nairobi.

Lea Toto is a community-based care program of the Children of God Relief Institute (COGRI) that aims to improve the quality of life for the children with HIV in its catchment area. The program currently runs CCCs with community outreach services in eight informal settlements in Nairobi County, namely, Kangemi, Kawangware, Dagoretti, Kibera, Mukuru, Dandora, Kariobangi and Zimmerman. These clinics serve as the centers for provision of holistic care services, including HTS and HIV treatment; they also offer food and nutrition services, psycho-social support and counseling, education and vocational training, socioeconomic support and economic-strengthening activities. The program focuses on children living with HIV, but also supports their caregivers and other members of the households in which they live, and the community as secondary and tertiary beneficiaries. Since its inception in 1998, Lea Toto has served 10,825

21 CDC Kenya 2015 Annual Report: https://www.cdc.gov/globalhealth/countries/kenya/pdf/cdc_kenya2015report.pdf
22 National AIDS and STI Control Programme (NASCOP) Kenya (2014). Ibid.
23 UNAIDS (2015). *Kenya Country Fact Sheet*: http://aidsinfo.unaids.org
24 Anjuli D et al. *Active referral of children of HIV-positive adults reveals high prevalence of undiagnosed HIV*. JAIDS Journal of Acquired Immune Deficiency Syndromes (in print): 10.1097/QAI.0000000000001184
25 Ministry of Health, NASCOP (2015) *National Plan for Accelerating HIV Care and Treatment 2015-2017.*
26 UNAIDS (2016). Ibid.
27 Ministry of Health, NASCOP (2015). *National Plan for Accelerating HIV Care and Treatment 2015-2017.*
28 John-Stewart GC et al. *Prevalence, perceptions, and correlates of pediatric HIV disclosure in an HIV treatment program in Kenya*. AIDS Care. 2013; 25(9):1067-76. doi: 10.1080/09540121.2012.749333.
29 Braitstein P et al. *'Wamepotea' (they have become lost): outcomes of HIV-positive and HIV-exposed children lost to follow-up from a large HIV treatment program in western Kenya*. J Acquir Immune Defic Syndr. 2011; 57e, 40–e46.
30 Anjuli D. Ibid.
31 John-Stewart GC. Ibid.

Table 1: Age of child at HIV diagnosis through APHIAplus

AGE AT HIV DIAGNOSIS	NUMBER OF CHILDREN
Under 2 (awaiting confirmation after 18 months)	112
2	51
3	89
4	115
5	133
6	149
7	148
8	186
9	209
10	207
11	196
12	200
13	212
14	175
15	167
16	162
17	136
18	113

children living with HIV and 54,125 of their extended family members. Services for children are aligned with the GoK's Minimum Service Standards for Quality Improvement of OVC programs. Support to family members has focused on building skills and competencies to provide care for people living with HIV. The program is currently serving 3,230 children of whom 2,779 are children living with HIV and 451 are infants who have been vertically exposed. Of the children living with HIV, 2,721 children are receiving ART, and the remaining 58 will be initiated on ART by the end of September 2016. Lea Toto also provides support services to approximately 16,150 household members of the children under their care.

In contrast, the APHIAplus OVC intervention is implemented in six counties of Kenya's Rift valley (Baringo, Kajiado, Laikipia, Nakuru, Nandi and Narok). This five-year (2011-2016) FHI360-led program is implemented as part of the larger comprehensive APHIAplus program[32] that supports the GoK and other partners to strengthen health facilities to deliver quality services, and enable communities to play a bigger role in identifying and solving health problems. Their focus on health service-strengthening activities includes HTS, including prevention of mother-to-child transmission (PMTCT); overall maternal and newborn and child care; reproductive health and family planning; tuberculosis (TB) and malaria resources; and voluntary medical male circumcision.

Since its inception in 2011, APHIAplus has registered 120,479 children between newborn and age17 years for program support, including 114,892 children (95% of all child

beneficiaries) who have been tested for HIV. The distribution across age of child at HIV diagnosis (Table 1) indicates the increasing urgency to promote testing for children older than five years, resonating with increasingly strong evidence around unexpectedly higher numbers of children with HIV who are slow-progressors.[33] Currently, APHIAplus is supporting 73,397 children from newborn to 17 years of age, including 2,885 (4%) with HIV. All but three have been linked to HIV treatment.

APHIAplus and Lea Toto are both closely aligned with the national response to HIV and engage community health volunteers (CHVs) as their front-line in-service provision. Both programs support a variety of activities that aim to strengthen the capacity of caregivers to provide quality care of their children. CHVs conduct home visits for the purposes of assessment, information sharing, coaching and skill building.

CHVs are mainly recruited from the government's pool of community health extension volunteers, and are very experienced and well respected. They work closely with their assigned families to provide advice and support for hygiene, nutrition, health care, education and socioeconomic development. Both programs provide households with economic-strengthening support, and link caregivers to social protection interventions, such as the OVC cash transfers provided by the government. They also generate referrals for HIV testing and facilitate linkages to services not offered directly by their programs, such as the care of adolescents with horizontally acquired infection, cases of gender-based violence (GBV) or health services beyond HIV-related care.

THE LEA TOTO PROGRAM APPROACH
Lea Toto (Swahili for "to raise the child") provides clinic- and community-based services, and facilitates access to government and other external services. Lea Toto clinics are freestanding and privately funded, use GoK guidelines and standards, and are typically staffed by a team of nine salaried employees, including a clinician, a nursing officer, an HTS counselor, two social workers, a nutritionist, a data entry officer, a driver and an office assistant.

Center administrators are responsible for clinic management, with one administrator overseeing four clinics. Lea Toto's community-based services are delivered by their 132 community health volunteers (CHVs), and include key case management functions (identification, assessment, delivery of basic support services that include parenting advice and adherence support, referral and follow-up), as well as community sensitization, home visits and facilitation of home-based testing and counseling. The population in the Lea Toto informal settlements is very mobile and consists mainly of people coming from rural areas where HIV-related stigma and misconceptions are significant, which underscores the program's continued focus on promotion of HTS.

Each Lea Toto CHV is assigned to about 25 children and visits each child at least once per month. During child monitoring visits, CHVs assess the child's health and nutrition and adherence to treatment, and provide health advice. They

32   APHIAplus builds on the successes of the 2006-2010 APHIA II Rift Valley program that was also led by FHI360.
33   Ferrand R et al. Survey of children accessing HIV services in a high prevalence setting: time for adolescents to count? Bull World Health Organ. 2010; 88(6):428-34.

Community health volunteer Jane Wangui Kogi is a familiar presence to Nancy Musimbi's girls in their home in Kawangare, a settlement in Nairobi.

also promote good hygiene and facilitate any necessary intervention, such as access to education or psychosocial support. If the child or household needs clinical services not provided by Lea Toto, the CHV will contact the relevant health facility through the local community health extension worker (CHEW). Since most CHVs served as community health extension volunteers before joining Lea Toto, they are able to leverage their longstanding relationships with their local CHEWs to ensure client referrals are honored.

Lea Toto CHVs are supervised and supported by Lea Toto social workers, who ensure follow-up of all children enrolled in that clinic and conduct home visits with each child at least once per quarter. Every month, Lea Toto CHVs attend two review meetings, one with the Lea Toto social worker who focuses on HIV case review, and one with the CHEW at the nearby public health facility; this meeting focuses on general health care management and GBV case review.

The Lea Toto process for promoting prompt uptake of HTS and secure linkage to treatment is comprised of five steps:

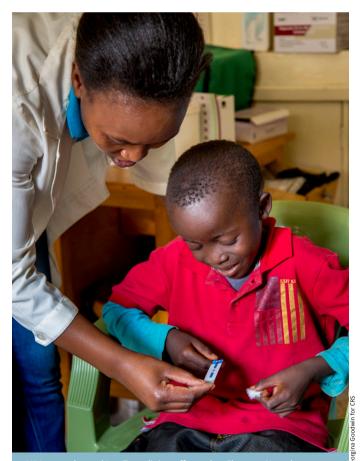### STEP ONE: GAINING ENTRY AND MOBILIZING FOR HIV TESTING

CHVs conduct weekly community mobilization that consists of door-to-door visits to talk about HIV and Lea Toto's services. They aim to visit every house in the catchment area once per year, and through discussion, assess where services are needed, while building a relationship based on trust and mutual respect over time. The CHV promotes HIV testing for both the caregiver and the children, and refers them to the nearest Lea Toto facility for testing services. In households where there are many children to be tested or the distance to the facility is a barrier, the CHV will arrange for the HTS counselor to provide home-based services for all household members. About 75% of Lea Toto's testing services have been provided in the home setting (by the HTS counselor), while 25% were provided at the clinic level.

STEP TWO: THE HIV TESTING PROCESS

Clients present at a Lea Toto clinic either following referral by a CHV, or through their own initiative. CHVs use a referral form on which they note their name, the name of the client, the service provider requested (counselor, social worker or nurse) and the reason for the referral (HIV testing, PMTCT, follow-up counseling, etc.). If the client wishes, the CHV can accompany them to the clinic. The client is first registered and then seen by the HTS counselor. After pretest counseling, the caregiver and children over nine months old are tested using rapid testing, and the results are shared immediately with the caregiver. For infants under nine months old, a dried blood spot sample is collected and sent to a Kenya Medical Research Institute laboratory for analysis. In this case, the caregiver is given an appointment two weeks later to receive the results.

STEP THREE: LINKAGE TO TREATMENT

Children who test seropositive are enrolled in treatment with the Lea Toto clinical program and the data entry officer generates a client ID for each child. The caregiver and child(ren) also meet with a social worker, who takes their social history; the nutritionist, who assesses their nutritional status and history; and by the clinician or the nurse, who collects a full clinical history. If the child is not ill, the Lea Toto clinician or nurse will do a blood test for CD4 count, viral load and liver function. The pharmacist will then provide treatment depending on the clinician/nurse's prescription. Adult caregivers who test seropositive will receive a referral to a government hospital for ART. CHVs provide adherence support to adult caregivers when they conduct household visits to the child(ren) and their caregiver.

HIV counselor and Lea Toto clinic staff member Florence Nyandwaro explains to her seven-year- old client the results of his HIV test.

Children who need services not provided by Lea Toto, such as TB testing and treatment, child protection and GBV response services and malnutrition treatment, are referred by the CHV to the nearest government health facility. Similarly, if the child is ill, the caregiver and child are sent to a government hospital for hospitalization and treatment. When the child has been stabilized, she/he returns to Lea Toto.

STEP FOUR: FOLLOW-UP AND ONGOING SUPPORT

The social worker describes Lea Toto's confidentiality and disclosure policies to the caregiver and child(ren), and explains that Lea Toto must be able to follow up on the client's status. The social worker also clarifies that the CHV is part of the clinic's team, and will thus be involved in the "shared confidentiality" regarding the client's status. They also explain that the program provides caregiver support group meetings, adherence sessions for caregivers, monthly follow-up clinic visits for the child, CHV follow-up visits at the home, support group meetings for children, life skills training for adolescents, supportive counseling sessions for caregivers and children and referrals to other services.

> *Phoenixes are always welcome to return to the program to share any challenges they might experience. After they have graduated, they will always be part of the Lea Toto family, and can come back for advice or guidance, or just a hug and a cup of tea.*
>
> —Lea Toto staff member

Finally, the social worker confirms the CHV with whom the caregiver and child(ren) will be working, and arranges a first post-test home visit. CHVs also provide adherence counseling and parenting support, and monitor the child's status during visits.

The program provides specialized HIV care and treatment packages to adolescents grouped by age, according to the GoK's national Adolescent's Package of Care, gradually evolving toward transition into adult care.

- **Explorers (10-13):** young adolescents who have just learned their status "explore" their knowledge about HIV status, living with HIV, being young adolescents, etc.

- **Sailors (14-16):** through exploration, the adolescents have gained knowledge and can use it to "sail" on in their lives, and start addressing challenges comfortably.

- **Achievers (17-19):** having explored, acquired knowledge, and successfully sailed on in their lives, these adolescents have now "achieved" experience that they can build upon to start helping younger adolescents.

- **Phoenix (over 19):** finally, having gone through the stages of adolescence, these young adults help prepare younger adolescents for adult life.

STEP FIVE: GRADUATION

Lea Toto's adolescent care activities, including post-disclosure clubs, monthly "young adults" days, quarterly recreational sessions and mentorship clubs, are designed to gradually prepare adolescents for transition to adult clinic care.

Lea Toto beneficiaries become Phoenixes when the program's social workers are sure they can manage on their own. Phoenixes are always welcome to return to the program to share any challenges they might experience. So even after a "Phoenix" has transitioned from Lea Toto's treatment program to an adult care and treatment program, ties to Lea Toto's psychosocial support may be released more gradually.

THE APHIAPLUS PROGRAM APPROACH

APHIAplus directly supports health facility-strengthening activities, and simultaneously works through local implementing partners to improve the quality of community-level interventions. All APHIAplus partners engage CHVs to provide home visits, apply the program's tools for client assessment and monitoring, and employ one data entry officer per partner to record data into the OVC Longitudinal Monitoring Information System (OLMIS). Each CHV engaged in the APHIAplus program supports about 30 children. CHVs are organized in clusters of eight to 12 (geographically), depending on the area they cover. For this case study, two of 17 APHIAplus implementing partners were visited: the Kenya Council of Imams and Ulaama (KCIU) and the Family AIDS Initiative Response (FAIR).

The KCIU is a faith-based organization established in 2001 that works through religious leaders (imams, ulaamas[34] and alimahs[35]) and administrative chiefs to raise awareness that HIV can affect anyone. It promotes HIV testing and treatment, and works to reduce stigma and discrimination against people living with HIV. The KCIU focuses first on mothers, ensuring that each mother knows her HIV status. Pregnant women and mothers with HIV are enrolled in community-level Prevention with Positives (PwP) support groups, and children in their care are enrolled in OVC program support. Children over two years of age receive home-based services through CHVs that include child and household status monitoring, adherence monitoring for children on ART, nutrition support (nutritional assessment, nutritional education and promotion of a balanced diet) and referrals for nutritional rehabilitation for those found to be malnourished. These families also receive expedited access to CCC services at GoK facilities (including HTS), immunizations and vitamin A for under-fives and psychosocial support for caregivers. CHVs are supported by field officers with professional backgrounds in social sciences and public health.

Family AIDS Initiative Response (FAIR) is a local NGO, also established in 2001, that works to address challenges faced by children who have either been orphaned by AIDS or live with parents who are sick or dying from HIV-related illnesses. FAIR's programs are based in drop-in centers, which are typically located in a church compound, where

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34 An ulaama (also spelled ulama or ulema) is a Muslim scholar who is recognized as having specialist knowledge of Islamic sacred law and theology.
35 An alimah is a female ulama.

anyone can drop in without risk of association with HIV service provision.

FAIR clients enter the drop-in center through referrals from health facilities or other stakeholders, or through self-referrals after learning about FAIR's services from other FAIR clients or during community-level information sessions. Children and their caregivers are enrolled for FAIR support if the child is living with HIV, orphaned by AIDS, living with elderly caregivers (such as grandparents) or living in a child-headed household. FAIR offers a robust package of services to address health and nutrition, education, psychosocial, social protection and economic needs. FAIR CHVs are supported by the social workers employed by FAIR.

APHIAplus partners apply a common framework to guide the work of CHVs, support their efforts and ensure the collection of quality data. All APHIAplus CHVs meet by cluster every month, supported by their supervisors. Cluster leaders chair the monthly meetings during which CHVs share experiences, discuss challenges, jointly identify solutions to their challenges, and promote best practices within their group. The APHIAplus process for promoting prompt uptake of HTS and secure linkage to treatment is comprised of the following six steps:

STEP ONE: GAINING ENTRY AND PROGRAM ENROLLMENT

While each APHIAplus implementation partner identifies children and families through slightly different entry points, they all seek to reach the most vulnerable children in their communities, especially those affected by HIV. When a child is enrolled for program support, the CHV will conduct the first home visit, and seek the signed consent of the caregiver for recording and management of individual data by the APHIAplus program. The signed consent form is then filed in the enrolled child's folder at the APHIAplus partner's office.

When consent is obtained, the CHV will complete the *Child Registration and Household Assessment Form*, which records the child's biodata and assesses the status of the household. CHVs submit the completed form to their supervisor, who verifies the data for submission to the data entry officer.

Fatuma Masika is a mother of five children and through her work as a CHV also meets with 25 children from 9 households. During a monthly forum meeting she holds up the group's trophy for the caregivers "winning dance performance."

Establishing a relationship with regular home visiting is a critical component of the APHIAplus program in Bondeni, a low-income settlement in Nakuru with a large Muslim population.

The data entry officer then enters the data into the OVC Longitudinal Management Information System (OLMIS). Analysis of the household assessment data helps determine each household's level of vulnerability, and determines the service package each should receive. However, determining the appropriateness of some services, such as economic services, requires more sensitive analysis and analytic tools. Depending on their needs and resources, families may be eligible for enrollment in National Health Insurance and/or relevant social protection programs for highly vulnerable households, savings and internal lending communities for the moderately vulnerable, and microfinance institution linkages for less vulnerable households.

STEP TWO: REGULAR HOME VISITS AND MOBILIZING FOR HIV TESTING

The CHVs conduct home visits to promote good hygiene and nutrition, facilitate birth registration, and promote the program's other services. Through this process, a relationship is forged between CHVs and clients, and the topics of HIV prevention, testing and treatment are raised. CHVs work over time with their assigned families to promote HIV testing and ensure that the HIV status of each enrolled child and his/her caregiver(s) is known.

STEP THREE: THE HIV TESTING PROCESS

Once caregivers have agreed to have their child(ren) tested for HIV, the CHV refers them to the public health facility's HTS. To facilitate this referral, the CHV uses the APHIAplus referral form, which is recognized by health facilities and by other affiliated service providers. The HTS provider counsels the client and provides HIV testing. HTS providers have typically earned a diploma in a social science (e.g., community development or psychology), as well as completed the NASCOP one-month HTS certification training. If the client is seropositive, the HTS provider requests their consent to disclose their status to a CHV to enable follow-up services. If the client agrees, the HTS provider will refer the client to the facility's CCC link desk, where the CHV contact will be formalized.

STEP FOUR: LINKAGE TO TREATMENT

The CCC link desks are staffed by a corps of experienced HIV-positive CHVs who are trained to coordinate case management and serve as a natural and effective bridge between community and facility, providing client tracking and defaulter tracing.

The link desk volunteer's role is specifically to support pediatric clients and their families to ensure that their linkage to treatment is smooth, and that, by removing community-level barriers to adherence, their retention in care is assured.

Link desk volunteers have a roster with phone numbers of CHVs working in the catchment area of the health facility. When they receive HIV-positive clients from HTS, they register them for clinical evaluation, ART and support group enrollment. They help with linking CCC clients to other health facility services, and enable home-based follow-up and adherence support by connecting the client with the CHV living in their neighborhood.

Link desk volunteers often work with "expert clients" to provide psychosocial support to clients. Expert clients are people living with HIV who have openly disclosed their

Link desks, located in the CCC, coordinate case management and provide client tracking and defaulter tracing. Staffed by a CHV living with HIV, link desks serve as a natural and effective bridge between community and facility.

status, and are trained and volunteering under the auspices of the larger APHIAplus Rift health sector-strengthening program. Each CCC is typically staffed by two link desk volunteers and two expert clients. Expert clients build upon their experience of living positively to support (generally) adult clients through peer counseling and psychosocial support, facilitate support groups that meet at the CCC, and help with client referrals, including accompanying clients to specific services within the facility and to community-based care and support services as needed. Both link desk volunteers and expert clients receive stipends in return for their voluntary work.

STEP FIVE: FOLLOW-UP AND ONGOING SUPPORT

CHVs make regular visits to monitor adherence and provide support. On a monthly basis, CHVs complete a *Child Status Monitoring* form for each child enrolled into care, and on a quarterly basis they complete a *Household Status Monitoring* form. They use mid-upper arm circumference measurements to monitor the nutritional status of their clients, measuring monthly for children and quarterly for adults. Using a standardized *Community Prevention with Positives* job aid, which includes 13 messages, they communicate at least one message on adherence and at least two other messages to their adult clients during the course of their visits.

Adherence to the clinical regimen is supported by link desk volunteers, who track each client's clinic attendance and assist in ART and TB defaulter tracing. At the start of every

Roles and Responsibilities of Link Desk Volunteers

- Receive and filter clients as they seek services at the facility

- Provide information on HIV services available

- Identify referral points for different services in the health facility and the community

- Network with other services within the facility to be sure service to clients is timely and integrated

- Refer clients from facility to any relevant available service points

- Direct and escort clients to services as needed

- Keep a referral diary

month, the data entry officer generates a blank *OVC Retention Monitoring Form* listing all enrolled OVC according to the CCC where they are registered for ART services. The forms are distributed to the CCCs, and the link desk volunteers use them to track the OVC clients presenting for their follow-up visits. This enables immediate follow-up if a client misses an appointment. The completed forms are collected monthly and the data entered into the OLMIS.

The APHIAplus program incorporates clinical data drawn from viral load monitoring to fully understand each child's response to his/her treatment regime. Through its strong partnership with the MoH, the APHIAplus program M&E officers have access to web-based data from three national referral laboratories, where they extract viral load test results on program beneficiaries for entry into the program's OLMIS. Access to this information ensures prompt intervention for enrolled children when needed. For example, if a child's adherence to medication is confirmed by the data obtained from both the *Child Status Monitoring* and *OVC Retention Monitoring* forms, but the child's viral

At this "Youth Friendly Centre" in Nakuru town, staff are trained specifically on pediatric and adolescent testing and counseling.

load is not suppressed, this may indicate that the treatment regimen should be adapted.

STEP SIX: OVC TRANSITION AND PROGRAM EXIT

Transition of adolescents living with HIV from pediatric to adult care and treatment services is closely managed by the program to ensure smooth entry. An *Individual OVC Transition Process Monitoring & Documentation Tool*, followed by an *OVC Exit Form*, are completed when a child reaches age 18 and transitions from program support, or when the household moves away, or if they opt-out of the program because they decide they no longer need program support. As with all other data, this information is entered into the OLMIS for monitoring and reporting purposes.

BRINGING CHILDREN TO HIV SERVICES

1. Expanding the reach of the HTS workforce

In their approach to training, both the Lea Toto and the APHIAplus programs use and disseminate MoH, NASCOP and MoEACLSP guidelines, national action plans, minimum standards and training curricula, as well as PEPFAR guidelines, and both programs engage government trainers to provide trainings. Both programs have complete confidence in the technical quality of GoK materials and the GoK's ability to guide health, psychosocial, nutrition, education, child protection and social protection services. The partnership between APHIAplus, MoH and NASCOP, articulated in a robust Memorandum of Understanding, was lauded by many case study participants as an important enabler for community-facility collaboration.

Both Lea Toto and APHIAplus work with CHVs who have been deliberately recruited from a pool of trained community health extension volunteers, and whose previous volunteer experience prepares them to effectively function as a "hub" to enable a comprehensive response. To expand a CHV's skill base to include recognition and management of a wide range of OVC needs, APHIAplus developed a CHV training curriculum supported by standard operating procedures and a variety of job aids and tools. The APHIAplus five-day training curriculum[36] complements the MoH national curriculum for community health workers.[37] With these added skills, CHVs assume an expanded role with a focus on service to children and a mandate to link children and households with health facilities and other service providers.

While neither program recruits volunteers on the basis of HIV status, efforts to involve those living with HIV in programming and the deliberate recruitment of experienced caregivers have resulted in the strong participation of individuals living with HIV in the CHV workforce. Lea Toto staff reported that approximately 50% of their CHVs are living with HIV. Staff in both programs, as well as health service personnel, shared that the thoughtfully conveyed disclosure of status by an HIV-positive CHV is a powerful influence in a reluctant client's decision to undergo HIV testing.

Leveraging this strength, APHIAplus CCCs engage HIV-positive CHVs as link desk volunteers to facilitate referrals and client

Initiative Response (FAIR) in Nakuru, young people enjoy tea and are linked to a range of services that include HIV testing and counseling, HIV prevention, life skills education, care and treatment and economic strengthening.

Photo by Georgina Goodwin for CRS

tracking, augmenting the work of expert clients who provide psychosocial support. Building on their core knowledge and preexisting expertise, Lea Toto and APHIAplus provide additional training to their CHVs by focusing on the role that community volunteers can play in enabling early HIV detection, treatment and adherence in children, and including issues such as managing confidentiality, disclosure, living positively with HIV and child protection.

The establishment of link desks has expanded the MoH's ability to coordinate case management by creating a bridge between the children, their caregivers and the facility. Placing an experienced CHV at a link desk in the CCC augments the expert client cadre by focusing specifically on children, providing an extra pair of hands in the clinical setting where demand for services often outstrips the supply of skilled providers. To help with the establishment and multisectoral functioning of the link desk, APHIAplus has developed an orientation guide for service providers and stakeholders that explains the role of the link desk, the steps involved in setting up and locating it, how to engage stakeholders in the development and rollout of link desks, the roles and responsibilities of volunteers at the link desk, provision of management and support to the link desk volunteers, and documentation and reporting processes.

2. Drawing strength from a social work perspective

The case study interviews revealed that in both programs, the presence of social workers on staff improved the quality of support group facilitation, management of disclosure with children and provision of individualized psychosocial support. Bringing a social work perspective to a historically health-centric intervention area allows the program to meet a range of needs to ensure best possible health outcomes for children and their families.

At Lea Toto, the influence of the social work perspective is particularly apparent in its commitment to support group development. Support groups are carefully structured to

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36   The APHIAplus curriculum is designed to be delivered as a five-day initial training followed by a three-day refresher training. APHIAplus Nuru ya Bonde (2012). Care and Support for Orphans and other Vulnerable Children, Training Curriculum for Community Health Volunteers.

37   Community Health Volunteers Integrated Curriculum (http://www.communityhealthservices.or.ke/images/pdf/chv_integrated_curriculum.pdf)

address specific social and emotional challenges. For example, Lea Toto engages "expert caregivers" to provide support to newly formed support groups. Lea Toto's expert caregivers are not specifically trained, but are carefully selected through a formal review of their successful history with the program and their demonstrated ability to serve as role models for other caregivers. They typically demonstrate success with health and psychosocial care of their child(ren), effective implementation of self-help opportunities and economic strengthening initiatives, and an affinity for community networking and service. Eventually caregiver groups graduate into self-help groups that focus on economic empowerment opportunities. Lea Toto also provides life skills training for caregivers, which are organized along with monthly disclosure meetings that assist caregivers with disclosure of their own status and their children's.

At APHIAplus, not all implementing partners engage social workers, illuminating the differences in staffing structures and the advantages of including a social work perspective. Among programs with social workers on staff, case study interviews revealed a higher degree of sensitivity for child-level distress, and an enhanced ability to facilitate the child's acceptance of their status, live positively with HIV and adhere to treatment.

3. Serving children and adolescents living with HIV

Reluctance to reveal a child's positive serostatus to the child is common among parents, caregivers and even service providers. Reluctance is generally related to HIV stigma, and among parents who were themselves living with HIV, stigma imposed a double burden; parents who had not come to terms with their own HIV status are likely to find it even more difficult to disclose their child's HIV infection to their child. For mothers who have not disclosed their positive status to their husbands, study respondents described the risk of domestic violence and rejection as "very high," especially in the Muslim community. Acknowledging that there is a lot at stake, both Lea Toto and APHIAplus programs took great care to develop supportive approaches whereby HTS providers, CHVs and link desk volunteers (with support from social workers) work together to support the caregiver throughout disclosure.

Disclosure is typically a progressive process, often guided by the child's questions and by viewing these questions as indicative of their learning needs. Once the process has started, child and adolescent support groups play an important role in facilitating the child's gradual absorption of information, acceptance of HIV status, adoption of a positive living lifestyle and commitment to treatment adherence. During the case study interviews, children and youth shared how their support groups helped them improve their psychosocial well-being (acceptance of self), and indicated that groups had become socially important as well as places to meet and make friends they can trust.

However, case study interviews revealed significant gaps in the collective understanding of the disclosure process as it applies to children with HIV. While most caregivers disclose the child's status at approximately 12 years of age, many youth and CHVs believe that earlier disclosure, around the age of eight years, produces a better outcome. Several young people described being between eight and 12 years old when they began asking specific questions and receiving unclear, incomplete answers. In response, they experienced depression and anger, sometimes even rejecting treatment or discarding their drugs. At Lea Toto, some children who were informed "late" (defined here as around age 12 years or older) experienced serious depression and attempted suicide before they came to accept their status. In contrast, those who were told when they were younger seemed to have felt more empowered.

Lea Toto's robust array of adolescent care activities was informed by a survey conducted among youth and subsequently designed to gradually prepare adolescents for adulthood and transition to adult clinic care. Adolescent care activities include post-disclosure clubs, monthly young adult days, quarterly recreational sessions and mentorship clubs. The program also provides them with vital skills and information concerning reproductive health, goal setting and career choices and socioeconomic resilience and success, helping them seek and negotiate support to address their needs and maintain safe behaviors in their future as young adults. Lea Toto expects their adolescent care program to equip individual young people with the capacity to positively influence their peers, as well as younger children.

While most caregivers disclose the child's status at approximately 12 years of age, many youth and CHVs believe that earlier disclosure, around the age of eight years, produces a better outcome.

To support these efforts, Lea Toto has developed several tools and approaches, including a set of guidelines outlining age-appropriate psychosocial services. The guidelines take into account children living in informal settlements, as well as those in family-based alternative care. Children with issues that need professional consultation and support, including psychiatric care, are referred and followed up until they fully recover. Where necessary, a family member is trained to provide day-to-day psychosocial support.

Lea Toto has also developed a comprehensive life skills curriculum for HIV-positive children between eight and 12 years old that addresses common challenges and prepares them for eventual disclosure. After disclosure, children with specific issues are provided individualized counseling services. For children who cannot attend life skills sessions because they are in boarding school or live far from the CCC, special sessions are organized.

In addition, Lea Toto encourages adolescents who know their status to form post-disclosure clubs where they receive group therapy, share their challenges, and provide moral support to each other. Various strategies are used to empower adolescents to take more responsibility for their health care, treatment, life in general and to cope with any emerging life issues. Monthly post-disclosure club activities include facilitated group discussion on specific topics, brainstorming, role-play, debates, games and exercises and creative writing.

Lea Toto staff also provide sexual and reproductive health education and rights education.

Every month, Lea Toto organizes a Young Adults Day in each of their eight centers, during which adolescents can attend clinics. Besides conducting general health assessments, staff focus on addressing the unique needs and issues faced by adolescents, either one-on-one or through group discussion. All children and youth with HIV are also invited to quarterly recreational therapy sessions that serve to strengthen interpersonal interaction and communication. During these recreational sessions, Lea Toto staff members observe children and youth to identify any issues that might require further support.

To prepare for program exit, adolescents ages 16 to 18 years who know their status form Mentorship Clubs, where an adult mentor is attached to each adolescent. Adult mentors, who may (or may not) be living with HIV, interact with adolescents as mentors, guiding them on general life principles. Lea Toto's Transitioning Toolkit is used to prepare the adolescents to exit from program support, and transition to adult care in a CCC. Adolescents are encouraged to raise issues that concern them before they exit, and are provided two years of follow-up to ensure they have successfully established themselves in a new HIV treatment setting with new service providers.

Conclusion

PROMISING PRACTICES

1. Lea Toto and APHIAplus program volunteers are trusted members of the HIV care and treatment team, allowing them to present a "one team" approach to client care. The mutual respect between the Lea Toto and APHIAplus program volunteers and clinical health care workers allows them to assist and support clients while respecting confidentiality. In both programs, respect for confidentiality of the client's status is key to winning the trust of their clients. In APHIAplus, clients provide formal consent during program enrollment, allowing the program to track each client's status. In Lea Toto, the HTS counselor obtains verbal consent. In both cases, agreement is obtained from the client in a straightforward manner.

To earn this trust, these programs have demonstrated a clear commitment to supporting GoK leadership, reinforcing government priorities, adhering to government (MoH, NASCOP and MoEACLSP) guidelines and engaging government trainers to provide training. The fact that these programs are so clearly guided by government strategies and nested in the government's response to HIV gives them credibility. It also enables them to adapt rapidly to updated government guidelines. For example, both programs responded quickly and with enthusiasm when new HIV guidelines required *all* HIV-positive clients – both children and adults – to be initiated on ART irrespective of CD4 count by the end of September 2016.

2. The APHIAplus program has developed a superior management information system for handling client data over time and program monitoring. This OVC Longitudinal Management Information System (OLMIS) is remarkable for its user-friendliness and for the quality and completeness of the data it generates. This system contains the following types of data:

- Biodata

- Needs assessment of the child

- Household vulnerability assessment
- Service monitoring
  - Linkage to care
  - Monthly child-level service monitoring
  - Quarterly household-level service monitoring
- Viral load tracking and adherence monitoring
- Client transition and exit

The data collected by CHVs and social workers is entered into the OLMIS by each partner's dedicated data entry officer. The data entry officers interviewed characterized the data entry and management process as "not cumbersome," saying that they could easily manage data of more than 500 children per month.

The OLMIS is extremely practical to use, and provides a wealth of accurate, relevant, user-friendly data. It runs on a Microsoft Standard Query Language (SQL) platform. While the data entry officer responsible for data entry and the generation of reports should be familiar with basic computer software, no specific information technology expertise is required. Data can be entered off-line – the OLMIS database updates automatically when internet connectivity is established.

3. The ability of APHIAplus to link adherence support with viral load monitoring, at scale, is a potential game changer for the care and treatment of OVC living with HIV. As more children with HIV are identified and start ART earlier with presumably higher CD4 counts, viral load monitoring to detect treatment failure and lack of adherence becomes increasingly beneficial not only to preserve health and achieve a normal growth trajectory, but to protect second-line treatment options as children age. The APHIAplus mechanism for merging adherence monitoring (through home-based observations and tracking of clinic attendance) with viral load test results is potentially both lifesaving and costsaving. APHIAplus has demonstrated that through establishing relationships that allow for sharing of relevant information, it is possible to monitor the progress of each child on treatment *at scale*.

4. Programs with built-in social work capacity add value by protecting health sector investments over the long term. The observations drawn during the case study interviews revealed a clear advantage for programs that employ social workers (Lea Toto and APHIAplus/FAIR) relative to where they do not (APHIAplus/KCIU). Social workers, by virtue of their professional orientation, are sensitive to the critical nonclinical needs of children with HIV, and are able to anticipate the support they might require. They are attuned to the subtle clues that indicate child distress and able to provide age-appropriate assistance. They also benefit from collegial connections with relevant service providers such as adolescent psychologists, GBV service providers and child protection officers. All of these inputs aim to improve psychosocial health, adjustment to disclosure, commitment to positive living and improved treatment adherence.

Similarly, bringing OVC literacy to the community health extension volunteer cadre ensures the swift identification and response to the combined vulnerabilities of child protection violations and HIV. The Lea Toto and APHIAplus/FAIR programs have demonstrated practical, effective methods for merging the health and social services provisions for the benefit of the whole child and his/her family. Through deliberately recruiting social services staff to support and manage the CHV cadre, these programs were able to ensure that the health benefits of HIV testing and treatment would be maximized and sustained over time.

5. The Lea Toto program has developed a full array of adolescent activities specifically designed to empower children and youth with HIV to participate fully in their treatment plans, make life choices that support positive living and long-term health, and assume full and satisfying adult lives. Empowered children and adolescents living with HIV also play a very important role as "ambassadors," helping others who are living with HIV come to terms with their situations, live positively, and build a better future.

6. The APHIAplus link desk volunteers are a unique and important adaptation of the "expert client" model with a focus on children through a holistic care lens, ensuring that available community resources are fully utilized and serving as an effective community-facility bridge. HIV-positive volunteers, or those who are caregivers of HIV-positive children, are able to use their own experiences to assist parents and caregivers to overcome fear, denial and misinformation. The volunteer's carefully timed disclosure of HIV status and sharing of personal experiences provide a unique and sometimes critical brand of influence.

CHALLENGES AND GAPS IDENTIFIED

Better data and stronger guidance are needed to understand the process and timing of disclosure to children. This is a crucial element in forging and sustaining a successful link to treatment. This presents a tremendous opportunity to promote and engage the voices of children and adolescents in planning, implementing and evaluating new guidance.

Evidence regarding the effectiveness of the various support group formats and methodologies for children and adolescents is needed to underpin clear guidance and a secure resource stream. While youth activists for HIV prevention have been very influential over the past two decades, youth leadership and mentorship of child-focused support groups have not gained any real traction. Retreats, workshops, camps, regular self-help meetings, mentorship, help lines and other formats have been implemented, but have yet to generate evidence of their success in achieving treatment adherence, psychosocial health or successful transition to adult life. It would be helpful if OVC programs could implement an indicator to capture the number of OVC who have successfully transitioned to adult care.

Stigma is still a major barrier to the provision of HTS for children, in particular because children are often dependent on their mothers to initiate testing. For a mother who is afraid to learn her own HIV status, or who fears that she will be

forced to share her status with her partner if her child tests positive, the risks of beating, abandonment, separation from her other children and shaming in front of family and friends are very real. For children living with nonbiological caregivers, denial of possible infection and fear that the child will suffer discrimination continue to delay uptake of this important service. It is vital that Kenya continue to build HIV-competent communities that protect children through awareness of child protection threats, increased male involvement in parenting and child health and improved social support to children with HIV and their families. Efforts to reduce misinformation and reduce stigma and discrimination for people living with HIV should include a particular focus on children with HIV.

Approaches to more rapid, systematic identification of children with horizontally acquired HIV are still lagging. Young married girls, victims of rape and all children who are willingly or unwillingly engaged in sexual activity need access to child-friendly HIV information and HTS services. APHIAplus and Lea Toto have not developed approaches to address the specific needs of children with horizontally acquired HIV.